

Experiences of women with endometriosis: An Interpretative Phenomenological Analysis.

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Declaration

I declare that all the work included in this thesis is my own except where otherwise stated. No portion of this work has been, or will be submitted for any other degree or professional qualification.

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Abstract

Background: Endometriosis is a common, yet enigmatic chronic gynaecological condition, with an unknown aetiology and no cure, affecting approximately 6-10% of females of a reproductive age. Symptoms include heavy menstrual bleeding, pelvic pain, fatigue and infertility which has a negative impact on daily living. Clinical research aiming to establish the cause of the condition and to develop treatments is ongoing; however, there is a lack of research investigating what it is like to live with the disease.

Aim: The aim of the study was to examine the experiences of women with a surgical diagnosis of endometriosis.

Methods: Semi structured interviews were carried out with 13 women. Interviews were transcribed verbatim and data analysed using Interpretative Phenomenological Analysis (IPA). Analysis revealed five key themes: making sense, impact on daily life, identity, taking back control and legitimisation.

Results: Women reflected upon the journey they travelled in trying to make sense of their symptoms. Diagnosis enabled a fuller understanding of their condition and facilitated increased knowledge and support. The condition impacted on all aspects of daily life and psychological outcomes to the point where women felt controlled by the disease. Identity and sense of self was challenged through changes in their ability to fulfil expected social roles, with women trying to maintain their past identities by minimising the reality of their symptoms. A variety of coping skills were employed to take back control over their lives. Finally, normalisation of symptoms by medical professionals, family members and lay public reduced the legitimacy of the condition and made self-management difficult.

Conclusion: There is a general lack of knowledge, acceptance and support for women with endometriosis. Qualitative studies such as this one add the contextual information required to understand what it means to live with endometriosis. However, improving the quality of life of women with this debilitating condition requires further understanding of their lived experiences.

1. Introduction

1.1 Endometriosis epidemiology, aetiology and treatment.

The definition of endometriosis is given as '*the presence of endometrial-like tissue outside the uterus, which induces a chronic, inflammatory reaction*' (Kennedy et al., 2005, p. 2699) and is associated with chronic pelvic pain, deep dyspareunia (pain during or after sexual intercourse), severe dysmenorrhoea (painful menstruation), ovulation pain, infertility, fatigue and bowel problems such as constipation or diarrhoea (Kennedy et al., 2005). Many of the symptoms are caused by the responses of the endometrial like tissue to the monthly hormonal cycle and oestrogen, causing the tissue to swell and bleed. This results in pain and the formation of fibrous tissue, called adhesions, which can attach to and restrict the internal organs (Endometriosis.org, 2011). This chronic gynaecological condition is thought to affect approximately 6-10% of the female population of a reproductive age and can have a significant negative effect on quality of life (Giudice & Kao, 2004). The condition also has a major economic impact, with an estimated cost of \$22 billion per year from direct health care costs, direct non-health care costs (e.g. childcare while admitted to hospital) and in-direct non-healthcare costs such as lost work productivity (Simeons, Hummelshoj, & D'Hooghe, 2007). Another study by Simeons, Meuleman and D'Hooghe (2011) has estimated in Europe, these non-healthcare costs to be as much as €4943 per person over a 30 month period, depending on the severity of the condition.

Despite the first reports of the condition in 1860 by Von Rokitansky (as cited in Giudice & Kao, 2004, p. 1789), to date, the cause is unknown, there is no cure for the condition and treatments mainly aim to reduce pain and infertility (Giudice & Kao, 2004). The condition is often classed as an 'enigma' as although there are typical symptoms, these symptoms also mimic other diseases such as Irritable Bowel Syndrome (IBS) or Pelvic Inflammatory Disease (PID) which

can make diagnosis difficult. As a result, the gold standard for diagnosis is through visual inspection during laparoscopy (Kennedy et al., 2005). In addition, although classification systems have been created to describe the severity of the disease, there is no correlation between pain or symptoms experienced and the classification systems. This means a woman with a classification of minimal disease may experience severe pain, or in other cases, women may have no symptoms at all and advanced disease is found coincidentally during investigation for other medical conditions (Kennedy et al., 2005).

As previously highlighted, the treatments offered to manage the condition are aimed at reducing pain and reducing the impact of infertility. Medication is one method of providing relief from pain. Women often use a range of analgesics to reduce pain and non-steroidal anti-inflammatory drugs (NSAID) are also commonly used. However the evidence regarding the pain reducing effect of NSAIDs is inconclusive and there are side effects associated with their usage (Endometriosis.org, 2011; European Society of Human Reproduction and Embryology [ESHRE], 2007). Treatments which manipulate hormones, mainly to suppress oestrogen are also commonly prescribed to manage endometriosis associated pain and achieve some degree of success. There are a variety of hormone treatments, varying from the combined oral contraceptive pill, to those which induce a pseudo-menopause, and therefore have a range of associated risks and side effects. Therefore it is recommended that decisions over which medical treatment to use be made on an individual basis (ESHRE, 2007). In addition to medical treatment, surgical treatment to remove lesions and adhesions and to restore anatomy to normal can also be performed to manage pain symptoms. This is usually done as a laparoscopic treatment and can be carried out as day surgery. However, a full laparotomy may be required to remove severe endometriosis. Similarly, radical surgery such as a partial or full hysterectomy may be required in severe cases. Evidence suggests that surgical treatment can be effective in the reduction of pain. However, the evidence is limited due to the short follow up

times of the randomised controlled trials (RCT) which have been carried out, reducing the clarity of the conclusions that can be drawn (ESHRE, 2007).

If endometriosis related infertility is diagnosed, evidence suggests that hormonal treatments are not effective and, due to a reduction in opportunities for conception, may reduce the chance of pregnancy (Kennedy & Moore, 2006). Surgical treatments to remove minimal to mild endometriosis have been found to be successful at reducing endometriosis related infertility. However, it is not possible to draw firm conclusions regarding the success of surgical treatment to remove moderate to severe disease in reducing endometriosis related infertility, as no RCTs have been carried out, and other studies differed in the procedures used (ESHRE, 2007; Kennedy et al., 2005).

Much of the research that occurs in relation to endometriosis is aimed at investigating possible causes of the condition and medical and surgical treatments. Other quantitative studies have looked at issues relating to quality of life; however, there are fewer qualitative studies that examine the experiences of women living with endometriosis. The next chapter provides a summary of the relevant quantitative research and a synthesis of the qualitative literature looking at women's experiences with endometriosis.

1.2 literature review

1.2.1. Introduction

As highlighted in the introduction, endometriosis is an enigmatic condition with an unknown cause and no cure. The condition can negatively impact on a woman's life and although there have been many quantitative studies investigating the aetiology and treatment of the condition

(Giudice & Kao, 2004), not as many studies have looked at the impact this long term condition has on the lives of the women diagnosed with it and those that do often use quantitative methodology. For example, a systematic review carried out in 2012 by Jia et al looked at the health related quality of life in women with endometriosis. The authors took several steps to minimise bias in the review by only examining studies which used standardised quality of life instruments, had sample sizes over 30 and met a strict inclusion criteria. They found 39 studies which met the inclusion criteria which were rated for methodological quality using a 14 point checklist. These quality ratings were then used in the data synthesis to define five levels of evidence ranging from strong to no evidence present. Of these studies, 9 looked only at the impact of endometriosis on health related quality of life, and the remaining 30 studies looked at the impact of treatment for endometriosis on health related quality of life (HRQoL).

Of the nine studies, five compared women with endometriosis to a control group. These studies reported that there was strong evidence that women with chronic pelvic pain due to endometriosis had a reduced quality of life in comparison to healthy controls. Specifically, with the exception of role related emotional functioning, endometriosis negatively affected all domains on the Short Form 36 (SF 36) Health Survey. In addition, work productivity and sexual dysfunction was also shown to be negatively affected. However, when comparing the HRQoL of women with endometriosis related chronic pelvic pain (CPP) to those with non-endometriosis related CPP, there was conflicting results. One large study, looking at a sample of 1332 women, reported that women with endometriosis related CPP had a reduced HRQoL compared to those with CPP not related to endometriosis. However two studies with smaller samples found no difference between the two groups in HRQoL.

The review looked at the impact of different confounders which can also impact HRQoL in women with endometriosis. These confounders included demographic factors such as: age, income, education, employment, marital and fertility status. Similarly, they also included factors

such as stage of disease, pain severity, duration of symptoms and whether the women exercised. It was found that income, education and marital status were not correlated with HRQoL (moderate evidence level), whereas, there was inconclusive evidence that age was negatively correlated with HRQoL. There was 'weak' evidence to suggest that being in employment was positively associated with HRQoL.

There was inconclusive evidence that fertility status, disease stage and duration of symptoms was negatively associated with HRQoL, and weak evidence to suggest that exercise was positively associated with HRQoL. Unsurprisingly, there was strong evidence to suggest that pain intensity was negatively correlated with HRQoL.

Finally, this study looked at the impact of treatment for endometriosis on HRQoL. In relation to medical treatments, there was strong evidence that the use of hormonal suppression was positively correlated with HRQoL. There was weak evidence that therapy with oral contraceptives, Danazole and Progestins resulted in similar improvements in HRQoL as hormonal suppression therapy.

In relation to surgical treatments, there was strong evidence for conservative surgery and moderate evidence for colorectal resection in increasing HRQoL. Other surgical procedures, such as laparoscopic uterosacral nerve ablation (LUNA) and presacral neurectomy (PSN) were found to be the same or better than conservative surgery in improving HRQoL, however, the evidence for these procedures was weak.

Complementary therapies were also examined, specifically diet, acupuncture, Chinese Herbal Medicine (CHM) and progressive muscle relaxation (PMR). Dietary therapy, acupuncture and PMR all showed improvements in HRQoL, with CHM failing to show any improvement. However, the evidence for all of these therapies was also weak.

Although these studies indicate that quality of life is negatively affected by the condition and that some treatments can result in an improve this, the studies do not explain how the condition leads to a reduced quality of life and what it is like to live with this condition. As a result, several qualitative studies have been conducted to highlight the day to day reality of living with endometriosis. The following section provides a summary of the issues raised by these studies.

1.2.2 Issues faced by women living with endometriosis

The following section of the literature review is based on a synthesis of the qualitative literature looking at the experiences of women with endometriosis. As part of this synthesis process, each of the studies selected were assessed for quality using the CASP appraisal tool (Critical Appraisal Skills Programme [CASP], 2006). As the CASP tool has 10 questions, each paper was given a score out of 10. A cut off score of five or higher was set for inclusion as this was felt to be a level which would achieve an acceptable amount of studies to be included in the review, but would allow the exclusion of papers with flaws that threatened the validity of the study. The lowest rating in the included studies was six out of 10. Where studies were rated lower on the rating scale, this was on the whole due to a lack of reflexivity demonstrated by the authors, a limited discussion of ethical issues and at times limited discussion of the data analysis process (e.g. Denny, 2004a; Seear, 2009c).

The first and most common issue faced by women with endometriosis is pain. Although pain is often considered simply to be a physiological response to a stimulus, qualitative studies have provided a richer understanding of the complexity of the pain experiences of women with endometriosis. For example, Denny (2004a, 2004b) has highlighted that not all pain is the same, and women are able to differentiate between endometriosis pain and what can be described as normal period pain. Words like 'overwhelming' and 'intense' have been used to describe the pain which, in some cases, is so severe that some women pass out, are sick or are

not able to walk or stand. The timing of the pain throughout the month often varies, with some women experiencing acute pain at the start of menstruation, or at ovulation. Other women report the pain to be constant and not in relation to their monthly cycle (Huntington & Gilmour, 2005; Jones, Jenkinson, & Kennedy, 2004). Similarly, pain can often be experienced in different parts of the body. As well as the commonly reported pelvic pain, other areas such as the back, hip joints and top of the legs can also be painful (Huntington & Gilmour, 2005; Jones et al., 2004). Women have also highlighted that several other bodily functions are painful because of the condition. These include painful urination and bowel movements, as well as pain during sexual intercourse (dyspareunia). As well as pain, other symptoms reported by women include bloating, bowel problems, heavy periods, fatigue, depression and generally feeling unwell (Huntington & Gilmour, 2005). Jones et al. (2004) noted that 'different discourses' were used to describe the pain with some women talking about it in terms of period pain, or dysmenorrhea, e.g., "dull period cramps", while others talked about it in language similar to being in "childbirth", e.g., like "labour pains". Still others identified their pain as acute in nature with "sharp" or "needle like" pain (p. 125).

The symptoms described above can result in significant disruption to daily life. A study by Gilmour, Huntington and Wilson (2008) highlighted that it was difficult to maintain "activities taken for granted by their peers" (p. 445), resulting in losses in education, employment and social relationships. Full time employment can be threatened through increased sickness absence and it may be necessary to rely on part-time employment making it easier to accommodate their condition.

As well as disruption to work, several studies (Denny, 2004a; Denny, 2004b; Gilmour et al., 2008; Huntington & Gilmour, 2005; Jones et al., 2004) have also reported that women experience a reduction in their social activities and networks. Women in these studies withdrew from social activities due to the difficulties in managing pain, bowel and bladder problems and

fatigue. In addition, women often take strong painkillers to manage the pain which can leave them unable to participate in social engagements (Gilmour et al., 2008). Often it is when this disruption becomes too much to manage, that women seek help from medical professionals (Manderson, Warren, & Markovic, 2008). As well as work and social interruption, performance of other activities of daily living such as cooking, cleaning or shopping are made difficult by the pain and other symptoms of the condition. Even fundamental activities, such as sleeping, eating, bathing and mobility are negatively affected (Jones et al., 2004).

Although partners are often cited as great sources of support (Denny, 2004a), the condition can also have a disruptive effect on relationships, especially intimate relationships with partners. Dyspareunia often results in women either suffering the pain during sex, stopping sex with their partners after it has started, or being unable to engage in penetrative sex completely (Denny, 2004a; Denny, 2004b; Denny & Mann, 2007; Huntington & Gilmour, 2005; Jones et al., 2004). However, Denny & Mann (2007) did report that some women were able to cope with the pain by changing sexual position. Despite this negative effect on an important part of life, this is an issue that is often not discussed with others or even with medical professionals. Denny (2004a) reported that even during medical consultations, women were reluctant to raise the issue with their doctors and that doctors also failed to query its occurrence.

Women often report that the condition has a negative impact on their self-esteem and their emotions. This was found to be the case in studies by Denny & Mann (2007) and by Jones et al (2004) where the impact of dyspareunia not only disrupted the women's sex lives, but also left them with feelings of inadequacy and guilt due to their inability to have sex and the effect that this was having on their partners. The women also felt unattractive and unfeminine, reducing their self-esteem further. Similarly, women also reported a sense of regret that they were unable to enjoy this part of their lives in the way that other women do.

Infertility caused by endometriosis can also have a significant impact on women's psychological outcomes. Jones et al (2004) found that women who wanted to have children but could not reported feelings of anxiety and depression. Feelings of inadequacy and the strain of trying to conceive often negatively affected their relationships with partners.

Women reported they felt controlled or 'ruled' by the disease, leading to feelings of frustration with the pain, often making them feel emotional and 'weepy'. Mood disturbances, attributed to hormones, can also negatively impact on the women, leaving them feeling irritable, 'ratty' and sometimes even 'violent' (Jones et al., 2004).

Social isolation and loneliness are commonly reported. Concerns that they will not be believed and that they will receive negative responses from others can lead some women to doubt their symptoms and be reluctant to disclose or discuss their condition. For example, Denny (2004a, 2004b) and Gilmour et al (2008) both reported situations where the women's claims that they were ill were not believed by co-workers and managers.

Finally, the lack of successful treatment options can leave women feeling frustrated, angry and disillusioned, mainly with medical professionals (Jones et al., 2004).

However, despite the condition having a negative impact on self-esteem and emotions, women have reported that making changes to their lifestyle and becoming knowledgeable about the disease has an empowering effect. They have also reported that the support received from support groups and charity websites has helped them to make these changes and take back some control over their lives (Gilmour et al., 2008; Huntington & Gilmour, 2005; Seear, 2009c) .

Another prominent feature of the illness is the level of uncertainty that accompanies it. Prior to and during the diagnostic phase uncertainty can be created due to the fact that symptoms of

endometriosis often mimic other conditions. Denny (2004a) highlighted IBS was often mistakenly diagnosed and treatments were prescribed which were unsuccessful, leading to more uncertainty and sometimes accusations from doctors of non-adherence to treatment. Receiving a diagnosis helped to reduce uncertainty by offering relief from the concern that the pain was caused by a more ominous condition, such as cancer (Ballard, Lowton, & Wright, 2006).

Uncertainty about the course of the disease can come from the range of hormonal treatments and surgical treatments that are used but that are often unsuccessful or successful for a limited period of time (Denny, 2009). This study also reported that the randomness and unpredictability of the symptoms led to uncertainty day to day. Denny (2004b) also raised the issue of uncertainty related to the long term effect of medical treatments and unpleasant side effects. In a similar way, those wishing to have children live with the uncertainty of trying to conceive, often having to go through In Vitro Fertilisation (IVF) treatment.

Finally, uncertainty relating to the future is due to the incurable nature of the condition and that treatments are not guaranteed to work for the longer term (Denny, 2009). However, this study suggested the way the women perceived the future depended on whether they were in pain at that current time, with those who were not experiencing pain having a more optimistic outlook. Despite this, it was generally believed that due to the nature of the condition, the pain would be likely to return at some point.

One commonly reported negative aspect of the endometriosis treatment pathway is the delay many women face in receiving a diagnosis. On average it takes eight years to receive a diagnosis in the United Kingdom (Hadfield, Mardon, Barlow, & Kennedy, 1996). Receiving a diagnosis is important as it not only reduces some of the uncertainty surrounding the symptoms; it also allows women access to support groups and the endometriosis community (Emad, 2006;

Whelan, 2007) . The reasons for this delay are multifactorial with successful diagnosis being hampered by the fact that there is no standard, non-invasive method of testing for the condition and that many of the symptoms mimic other conditions. However, qualitative studies have highlighted other factors which contribute to the delay.

One study in particular, by Ballard et al. (2006) highlighted delays at two different levels: the medical and the patient level. At the medical level, three factors were involved. As previously stated, the gold standard test for endometriosis is through observation during laparoscopic investigation. However, transvaginal ultrasound, a non-invasive diagnostic method that is sometimes used for diagnostic purposes, is less sensitive at detecting endometriosis than via laparoscopy (Bazot, Thomassin, Hourani, Cortez, & Darai, 2004). Therefore, false negative results are possible, leading doctors to be satisfied that there are no abnormalities causing the pain. Secondly, treatment of pain and heavy menstrual bleeding through the use of the combined oral contraceptive pill can reduce symptoms for a time, thus reducing the need for a diagnosis. However, women stop using the pill for a variety of reasons and often the need for a diagnosis returns when symptoms become problematic again. Thirdly, they found that women reported being dismissed or 'fobbed off' by their general practitioners (GP) and that their pain was normalised. Many women in this study, and other studies (Denny, 2004c; Denny & Mann, 2008; Emad, 2006; Jones et al., 2004) were told that menstrual pain is to be expected and there was nothing that could be done about it. Some were also told that the pain was psychological in nature. As well as the belief that menstrual pain was normal, the women in Denny and Mann's study (2008) highlighted a lack of knowledge on the part of the GP. This was illustrated by GPs providing advice based on information that is not based on evidence, for example, that teenagers are too young to have endometriosis or that getting pregnant cures the condition. Delays attributed to these reasons in particular led to feelings of frustration and even anger in some women (Denny, 2004b; Emad, 2006). However, women did not see lack of knowledge as an issue, if the GP was sympathetic and supportive in having the symptoms fully investigated by

referring to a gynaecologist (Denny & Mann, 2008). GPs appeared less likely to normalise menstruation when the woman presenting with pain was older (late 20s early 30s), thus fitting the stereotypical presentation of endometriosis, or if there were suspected fertility issues. In these circumstances, GPs were quicker to refer for further investigation as the symptoms and context were more suggestive of pathology (Denny, 2004b; Manderson et al., 2008; Seear, 2009a).

Diagnostic delays were also present at a second, individual patient level. This involved the women accepting the pain as normal and being unable to distinguish between what is regarded as 'normal' period pain and 'abnormal' pain. This normalising of symptoms was acquired through the women's learning of menstruation from their mothers and friends. Embarrassment and a lack of discussion about what was normal and what was not normal maintained this acceptance. Although family members and friends were sometimes instrumental in highlighting that severe pain was not normal, when it was normalised, this often acted to discourage women from seeking help, instead instilling the belief that they should be able to cope with the pain and therefore resulting in a delay in receiving a diagnosis (Ballard et al., 2006; Denny, 2004b; Denny, 2009; Denny & Mann, 2008; Manderson et al., 2008; Seear, 2009a). This description of the delay in seeking help was conceptualised by Markovic et al. (2008) as a pathway of 'endurance' that women followed in coping with the disease, and in their sample, was associated with a lower socio-demographic background. In contrast to this, they found other women followed a pathway characterised by 'contest'. Instead of accepting menstrual pain, these women rejected health professionals' normalisation of pain or diagnoses of depression. They found that being from a higher socio-demographic background, confident in 'rejecting the psychologising of their physical pain', and being able to navigate the healthcare system were all believed to account for some women receiving more support from their doctors. In view of these and other findings, recommendations have been made to help society and medical

professionals understand what a 'normal' menstruation experience consists of to reduce the suffering of women with the condition (Ballard et al., 2006).

As previously mentioned, lack of GP knowledge has been highlighted as problematic for women. Indeed, it has been suggested that women often feel more knowledgeable than their GPs (Denny, 2004b) and that the contested and incurable nature of endometriosis means that there is more scope for women to become expert patients, with medicine unable to provide all of the answers (Seear, 2009c). Therefore women are often encouraged by their doctors to take an active role in their own care with self-management techniques such as stress reduction, exercise and nutrition. Studies have highlighted that women at some stage make at least some lifestyle changes (Gilmour et al., 2008; Huntington & Gilmour, 2005). Both studies reported that making these changes did provide certain benefits. For example, women gained a sense of empowerment or experienced 'a turning point' in how they self-managed their condition. They also benefitted from learning transferable skills, increased confidence and generally living a healthier lifestyle.

However, Seear (2009c) also reported on the negative aspects of being an expert patient. The unpredictable nature of the disease and an unknown aetiology all made it difficult for these women to become expert patients. In addition, there is an increased workload from researching the condition, which is carried out mainly on the internet. Women reported that the amount of time they spent managing their health, was 'physically and emotionally demanding' especially as often it did not have the desired effect. This led the author to argue that 'management of endometriosis becomes a third shift', likening it to another form of work or labour. Many women felt obligated to do this work but that the responsibility adds to the stresses that they already face in living with the condition (Seear, 2009c).

Similarly, confusion and uncertainty about the validity of the information was created as the information provided was often complex and inconsistent. Whelan (2007) reported that women

found access to information and 'medical jargon' barriers to becoming experts but that they found strategies to overcome them. Similarly, Gilmour et al. (2008) reported that gaps in the information provided by doctors were also problematic for women. Despite this, women viewed their doctor's information as of 'critical importance' (p. 446).

Self-management and the avoidance of risk factors were highlighted as being an extensive and difficult task. Advice regarding lifestyle issues that were considered risk factors for endometriosis can be contradictory. Similarly, many self-care behaviours are impractical and financially prohibitive, leading women to make their own rationalised decisions about which self-care behaviours they would practice based on their own levels of expertise. This can result in a sense of failure or guilt about not being able to avoid all the risks (Seear, 2009b; Seear, 2009c).

2. Rationale for a qualitative study of endometriosis

As the review of the literature highlights, there are many issues faced by women with endometriosis. In summary, these studies describe how living with endometriosis can result in women feeling isolated, controlled by their condition and let down by medical professionals. The significant delay in receiving a diagnosis can be attributed to a lack of knowledge on the part of both medical staff and the women themselves. Once a diagnosis is received, even though women now have access to support from the endometriosis community, self-management remains challenging with uncertainty about the future course of the disease remaining.

The above qualitative studies mostly used either thematic analysis (11 studies - Ballard et al., 2006; Denny, 2004a, 2004b, 2009; Denny & Mann 2007, 2008; Gilmour et al., 2008; Huntington & Gilmour, 2005; Seear, 2009a, 2009b, 2009c) or grounded theory (four studies – Jones et al.,

2004; Manderson et al., 2008; Markovic et al., 2008; Whelan, 2007) as their method of analysis. Two authors also noted additional methods of Voice Centred Relational Method (Whelan, 2007) and the Interactive Model for data analysis (Seear, 2009a, b, c). Emmad (2006) does not explicitly state which method of data analysis was used

The methodology for each study, however, was less clear. Ten studies looked at the experiences and beliefs of women with endometriosis, three appeared to use constructionist methodology and in three studies it was not possible to determine which methodology was used.

Although experiences of women with endometriosis have been investigated, most studies have been conducted without the use of an explicit methodology. Therefore the use of Interpretative Phenomenological Analysis (IPA) in this study was adopted in order to get closer to the women's experiences, but with the clear guidance of an established epistemological stance. Specifically, the focus on the experience of the participants and on the contextual interpretation of the experiences (Larkin, Watts, & Clifton, 2006).

Health psychology as a discipline has also failed to consider endometriosis and its impact on the lives of those diagnosed with it as a topic for investigation, despite the condition affecting one in ten women and there are no published qualitative studies of women with endometriosis using health psychology theories. It is against this background that this study was conducted using IPA. This would contribute to the knowledge provided by the existing qualitative literature, but from an interpretative and phenomenological viewpoint, and also raise endometriosis as a condition worthy of additional research within health psychology. Studies which have taken a psychological approach to the study of this condition have used quantitative methods, and in general have focused on outcomes such as quality of life and levels of anxiety and depression (Fourquet, Baez, Figueroa, Iriarte, & Flores, 2011). Health psychology has examined how

people respond to, cope with and adapt to living with a chronic condition. The aim of mainstream health psychology is to develop theories which will predict health and illness related behaviour, and use these theories to change this behaviour and support people in their adjustment to illness (Crossley, 2000, p. 2). Several theories and models have been proposed by health psychology, which suggest the mechanisms through which people cope with an illness. These theories and models have been used to design psychological interventions intended to support self-management for a range of chronic illnesses. For example, cardiac rehabilitation often involves addressing cardiac beliefs, such as 'exercise is dangerous for my heart'. This belief can act as a barrier to increasing physical activity, which is crucial to recovery and secondary prevention (Maeland, J.G., & Havik, O.E., 1988). Similarly, many interventions focus on encouraging people to change their lifestyle behaviour or to adhere to medication to improve health outcomes. However, as these interventions are based on scientific quantitative methodologies, much of the focus is on demonstrating that the models have validity and can predict predetermined outcomes. Similarly, they are based on predetermined constructs which may not be relevant across different types of populations or conditions. As a result, through a process of objectification, they fail to address important aspects of the illness experience such as what it means to the individual and how these experiences are valued.

One model which is commonly used in relation to the management of illness is the common sense model (CSM) of illness cognition and behaviour, by Leventhal, Meyer and Nerenz (1980). This model proposes that the perception of a stimulus (e.g. a symptom) will activate parallel processing of information at the cognitive level (the illness representations) and at the emotional level (the emotional response). The illness representations fall into 5 different categories: identity, cause, timeline, consequences and control/cure and both the illness representations and the emotional responses will influence the selection of coping methods. Once a coping behaviour has been selected, it is then appraised for its success, with modifications being made to the illness representations or the coping procedure if required (Cameron & Moss-Morris,

2010). Although this model was derived and developed from qualitative studies of the way people interpret and respond to disease (Diefenbach & Leventhal, 1996), as a self-regulation model, it assumes that an individual uses a problem solving approach to return to a state of normality after an event which changes the status quo, such as illness symptoms or a diagnosis of a disease (Ogden, 2007, p. 52). An issue with this assumption is that the model is based on acute rather than on chronic illness. This means that, for the person with a chronic illness, return to a previously 'healthy' state may not be possible. The cause and cure/control representations proposed in the model are said to be important for defining the meaning of the stimulus and that these will influence the coping actions undertaken by the individual (Diefenbach & Leventhal, 1996). In conditions where there is a clear cause and cure/controllability factor, it may be easy to predict which coping actions a person will choose to cope with the condition. However it is not so clear what happens when there is no identifiable cure or methods of controlling the condition, such as in the case of endometriosis. Similarly, although the model suggests that illness is interpreted according to five preconceived constructs, the model was not developed through qualitative research with women with endometriosis. This opens up the possibility that some of the constructs may not be relevant in the experience of endometriosis, or that there could be other types of representations which have not been highlighted as yet.

Another psychological theory which is often used to explain how individuals cope with chronic illness is the Theory of Cognitive Adaptation (TCA, Taylor, 1983). This theory proposes a process of readjustment to a life threatening event or personal tragedy through a focus on three themes: searching for a meaning of the situation, an effort to increase control, or mastery over the event and an effort to increase self-esteem. In trying to understand the event or crisis and find meaning in it (in this case, the occurrence of symptoms or a diagnosis of endometriosis), individual's seek answers to questions such as 'why has this happened', 'what is the significance of the event' and 'what has caused it'. These attributions could be seen to be

similar to the 'cause' and 'consequence' illness representation proposed by the CSM. The second theme of mastery is focused on questions such as 'how can I prevent this from happening again' or 'how can I manage this from now on'. Again, there are similarities with these questions and the cure/control illness representations in the CSM. Finally, as events such as being diagnosed with a chronic condition can lead to reduced self-esteem, Taylor suggests individuals try to find ways to feel better about themselves. One way of doing this is by making downward social comparisons, whereby individuals compare themselves to individuals slightly worse off than themselves (Taylor, 1983). In relation to the CSM, this could be seen to be similar to coping actions instigated by the emotional responses to a health threat. Similar issues may also be present when relating this model to coping with endometriosis, in that it is not possible to identify a definitive cause of the condition, there is no known cure and methods of controlling the condition are not guaranteed to be successful. Taylor examined the TCA in relation to women diagnosed with breast cancer and found that despite there being no definitive cause of breast cancer, the women still tried to look for reasons why they developed the disease, such as stressful life events, exposure to carcinogens or hereditary factors (Taylor, 1983).

Although these models suggest the process in which people go through when presented with a chronic illness, without knowing what meanings and values people place upon their experiences of health and illness, it is not possible to understand what motivates people to think and behave in the way they do. Therefore, in adopting a qualitative methodology for this study, and in particular using IPA, it is hoped that it may be possible to further increase our understanding of what it is like to live with the condition.

3. Methodology

3.1 Methodology Rationale

The aim of this study was to explore the experiences of women with a diagnosis of endometriosis and the impact this has on their lives. As previously stated, health psychology theories and models do not provide the rich contextual information required to fully understand what it means to live with a condition; therefore adopting a qualitative approach was required to answer the research question.

Although previous studies have looked at women's experiences of living with endometriosis, to the author's knowledge, there have been no published studies that use Interpretative Phenomenological Analysis (IPA). This methodology was chosen because of its aim of exploring how individuals make sense of significant events in their lives, making it a suitable approach for this study.

IPA was developed as a method of carrying out experiential psychological research, and has been used within health psychology from the method's beginnings in the 1990s (Smith, Flowers, & Larkin, 2009). There are three theoretical foundations of IPA, namely, phenomenology, hermeneutics and idiography. It is phenomenological because its aim is not to produce an objective account of an event. Instead, it focuses on the study of lived experience, and in particular, experience which is of significance to the individual and the meaning that the individual places on that experience (Smith et al., 2009).

However, as it is not possible to directly access the lived experience of another person and interpretation is required, which makes IPA hermeneutic in nature. The researcher is actively involved in interpreting the individual's own interpretation of their experience. This is described as a 'double hermeneutic' where the individual tries to make sense of their experience, while the researcher is involved in trying to make sense of how the individual makes sense of their

experience. Therefore the researcher's own conceptions are involved in how they are able to form these interpretations. In addition, the double hermeneutic also takes the form of an empathic and also of a critical stance. On the one hand the researcher is trying to understand what it is like from the individual's perspective. On the other, the researcher looks at what the individual is saying from a different angle and asks questions of the account. The researcher's interpretation also has to take into account that although there is an assumption of a connection between what an individual thinks, how they feel and what they say, the individual may not wish to disclose or find it difficult to express their thoughts and feelings (Smith & Eatough, 2007).

Finally, IPA is idiographic in that the focus is on close analysis of specific instances of an individual's lived experience. From this, it is possible to make specific statements about that individual. This is in contrast to mainstream psychology, which generally takes a nomothetic approach, where the focus of analysis is at a group or population level, allowing only probabilistic generalisations to be made. Although IPA can be used to analyse the experiences of a group of people, the groups tend to be small and the analysis starts with a detailed analysis of each case before moving to analysing across cases for similarities and differences. This allows any patterns in the meaning of the shared experiences to be illuminated. These findings can be related to and add extra detail to existing nomothetic psychological research findings (Smith & Osborn, 2008; Smith et al., 2009).

3.2 Rationale for using semi-structured interviews

In order to analyse how people make sense of their experiences, it is necessary to allow participants to freely reflect on these experiences. Although it is possible to obtain this type of rich data through the use of focus groups, personal accounts or diaries, the semi-structured interview is the most commonly used method (Smith & Osborn, 2008). The benefits of the semi-structured interview are that it allows the participant the opportunity to tell their story, while the researcher is still able to discuss topics relevant to the research question. The researcher is

able use an interview schedule as a guide and probe deeper into novel areas, all of which helps to produce richer data (Smith et al., 2009). However, the disadvantage of conducting semi-structure interviews is that the researcher has less control over the interview process. This means that interviews can be lengthy and also more difficult to analyse (Smith & Osborn, 2008).

3.3 Semi-structured interview schedule

An interview schedule (Appendix 1) was devised for this study which aimed to allow the participants to freely tell their story of living with endometriosis. Therefore, as a general opening question, the women were asked if they could give a brief history of their story from when they first experienced symptoms to the present day. This was deliberately chosen to help the participants relax into the interview process by asking them to talk in general about their condition and their lives. The remaining questions, delivered in an open format, covered areas relating to: symptoms, cause of the illness, how the condition affects their life, coping and medical care. Finally, at the end of the interview, the participant was asked if there was anything they would like to add.

3.4 Ethical Considerations

Ethical approval for the study was granted by the Queen Margaret University ethics committee following submission of the ethical approval application form and study protocol. As part of this process, a participant advertisement document, information sheet and consent form were devised (see Appendices 2 - 4). The advertisement document was created in order to invite participants to take part in the research, and provided details on how to get involved. The information sheet provided details of: the researcher and institution, what the project was about, what taking part would involve, that all attempts would be made to maintain anonymity and that confidentiality would be maintained. The consent form asked participants to consent to taking part in the study and that they had understood what taking part in the study involved.

As it was anticipated that participants may disclose information which was of a sensitive and potentially distressing nature, a debriefing sheet was also devised (Appendix 5). The debriefing sheet contained information about support services for people with endometriosis, which participants could access if they felt that taking part in the study had raised issues that they needed support with. These support services consisted of two charities, one of which has a support help line manned by other women who have had endometriosis and have received training on supporting other women with the condition. In addition, details of other websites and books which may be of interest to the participants were included.

3.5 Study Methods

3.5.1 Recruitment

In order to recruit participants, the main UK charity, Endometriosis UK was contacted by email for advice on how best to recruit participants and if they had any means to advertise the study to their members. They advised it was possible to advertise by joining their chat room facility and leaving a message on the notice boards. However, this method involves gaining access to a space dedicated to members and it may not have been deemed appropriate by members for this forum to be used as a recruitment tool. The charity also has regional support group organisers, who have contact with individuals who have been diagnosed with endometriosis. There was a support group in the local area to the author, and therefore, it was decided that enquiries would first be made to this support group organiser. Other methods of recruitment were also considered, such as posting an information 'poster' in local areas frequented by local women, for example, in community centres, libraries and recreation/fitness centres. However, it was decided that this method would only be used if there was a poor response to requests via the charity.

The charity liaised with the support group organiser on the author's behalf via email, requesting that she contact the author directly for details of the study. The group organiser contacted the author and an email reply was sent containing details of the study and with a copy of the 'recruitment advert' and the study information sheet attached. The group organiser sent the email to support group members and other women she had contact with that it may have been relevant to. This circulated email generated 16 positive responses, from individuals expressing an interest in taking part. Of those 16, a purposive, snowball sample of 13 participants was identified, with whom interviews were arranged and carried out. The drawback of using this method was that it is unknown how many people the group organiser sent the initial invitation email to, so it is not possible to determine how many individuals did not respond to the email. Despite initially indicating an interest in the study, three women in the end, did not take part. In each case they did not respond to further emails and contact was lost.

3.5.2 Description of participants.

As previously described, all of the women were recruited through the Endometriosis UK charity, were from the central region of Scotland and were white. The average age of the participants was 34, with ages ranging from 23 to 46 years. With regards to employment, 12 of the 13 women included in the study were employed, with one participant describing herself as 'a stay at home mum'. One participant who was employed was currently on long term sick leave from her employment. All participants were married or in a long term relationship and four of the women had children. The average age of onset of symptoms was 16 and was based on the age in which they reported painful periods. However, for two women this was not necessarily the age that they considered the endometriosis symptoms to have begun instead reporting that their symptoms escalated at a later age. The average age of diagnosis was 29 years and the average length of time taken to receive a diagnosis in this study was 12 years. Again this figure was calculated on the basis that symptom onset was classified as onset of painful periods.

Table 1 Demographic Data

Demographic Data	N=13
Mean Age	34 (range 23-46)
Employment:	
Employed	12 (1 on long term sick leave)
Unemployed	1 (stay at home mum)
Relationship status	
Married	7
Single	5 (in long term relationship)
Divorced	1 (in long term relationship)
Ethnic status	White British
No, participants with dependants	4
Mean Age of symptom onset	16 (range 11-34)
Mean Age of diagnosis	29 (range 19-38)
Mean delay in diagnosis (years)	12 (range 1-25)

3.5.3 Procedure

Contact with participants was initially made via email with the participant information sheet and consent form attached. Sometimes contact was made by telephone if requested by the participant. If they were happy, arrangements were made for the interview to be conducted at a time and location that was suitable to them. Although mostly this took place in the participant's home, other locations that were acceptable to the participant were considered.

Participants were asked to read, and if possible print off and complete the consent form prior to the interview. However, if this was not possible, a consent form was offered to the participant prior to the interview taking place. Confirmation that the participant was happy to have the interview audio recorded and for their comments to be used as quotes in future reports or publications was sought verbally. Similarly, participants were advised that although all attempts to maintain anonymity would be made, they may be identifiable from their voice on the

recordings, however only the author and possibly the author's supervisor would have access to these. In addition, it was also highlighted that due to the specific nature of the topic being discussed, it may be possible for someone to identify them from the details of their experiences they provide, however that this would be unlikely. All participants advised that they understood the risks to anonymity and were happy to proceed. Interviews lasted on average 1 hour long, ranging from 2 hours 10 minutes to 40 minutes.

All interviews were transcribed verbatim and stored according to British Psychological Society ethical guidelines relating to storage of confidential research data, with voice recordings stored electronically on an encrypted memory storage device, and printed copies of transcripts and completed consent forms being stored in a locked filing cabinet (Ethics Committee of the British Psychological Society, 2009).

3.5.4 Analysis

In order to become familiar with the data, interview transcripts were read repeatedly. The process of transcribing the audio recordings assisted this process and at times, the transcripts were read in conjunction with the audio recording to enhance understanding of the text.

The data were analysed using IPA, with the procedures set out by Smith et al. (2009) used as a guide to inform the process of moving from the data to the development of themes, both within individual transcripts and across the group as a whole. For the first four interviews, a close analysis of each transcript was carried out, with comments and thoughts written in the right hand margin. These notes were categorised into three types of comments: descriptive, linguistic and conceptual (Smith et al., 2009). Emergent themes from the data and the exploratory comments were then recorded in the left hand margin. Themes that were related to each other were clustered and then patterns were looked for across the four cases. This generated a list of super-ordinate themes, which was then used as a framework to analyse the

rest of the corpus. Each remaining transcript was analysed, albeit in less depth, according to the framework, but still being open to the emergence of new themes. This approach to the analysis of larger samples allows the themes that are important for the whole group to be identified (Smith et al., 2009).

One transcript initially appeared to be considerably different to the transcripts of the other 12 participants. Therefore, in order to develop the emerging thematic framework, a negative case analysis was conducted. This analysis indicated that there were other themes which may be of more relevance to this individual and better reflect her particular circumstances. For example, this individual had a different presentation of the condition and was diagnosed after treatment for a different gynaecological condition that required surgery. The condition was being successfully managed with hormone medication and had a minimal impact on her daily life. Therefore, with the exception of the theme of making sense, the themes that emerged for the rest of the corpus were not as relevant for this individual. As the analysis progressed, the themes within the individual transcripts were compared against the themes in this negative case to see if they were similar. In this study, however there were very few aspects of this individual's story that related to the others. This was useful however as having awareness that it was possible to have a diagnosis of endometriosis but without the negative impact on quality of life, suggests that there is a wide variety of possible experiences and that it is not useful to assume that all women will be debilitated by the condition.

Once all transcripts had been analysed and no new themes had emerged, a new list of super-ordinate theme titles and sub themes was produced, covering themes that were representative of the whole group. In order to ensure representativeness of each theme, a table indicating the prevalence of the theme in the corpus was created (Appendix 6). Themes were kept if they were present in 50% or more of the transcripts. This criterion was included to increase the validity of the results (Smith et al., 2009) and led to some themes being removed or, if

appropriate, relocated within a different super ordinate theme. In the final write up, some subthemes were merged, for example, subthemes e & f of the superordinate theme of 'making sense' were merged to form 'barriers to making sense'. Similarly, the subtheme c (public / others – knowledge vs lack of knowledge) was separated into two sub themes 'public awareness' and 'support from significant others'. The themes were also checked against the data for supporting verbatim extracts from the participants to ensure that the themes were grounded in the data.

Five main themes were generated by the analysis: making sense of the condition, impact on daily life, identity, taking back control and legitimisation.

4. Reflections on the study

Using a qualitative approach to research such as IPA assumes an acknowledgement that the researcher has an impact on the research process and therefore the outcomes. In this section I consider the impact that I may have had on this study. As a female who has received a diagnosis of endometriosis, I had a personal interest in the topic. I was aware that there was a lack of knowledge in the public domain about the condition. However, I was also struck by the lack of psychological research investigating the impact the condition has on women. As I knew that the disease was chronic and could lead to significant negative physical and emotional outcomes, I felt that health psychology was ideally placed to research the topic.

Although my own diagnosis gave me insight into the experiences of the women in the study, I was acutely aware of the need to remain as impartial and unbiased as possible. I believe having a personal experience of the condition allowed me to be more empathetic towards the

participants, which in most cases I believe made developing a rapport with the participants easier.

However, at first during the interviews I was aware that I was finding it difficult to maintain a balance between maintaining a rapport by being accepting of what was being said, and being impartial to what was being said. At times, when I was using positive body language, listening and attending skills, I was concerned that this would be misconstrued as agreeing with and endorsing what was being said which may have led the participant. Similarly, when participants disclosed how they felt they had been dismissed by medical professionals and the treatment they had received, it was difficult not to feel a sense of anger and injustice on their behalf and I had to try to remain objective.

Some of the women asked me why I was interested in endometriosis as a topic and if I also had the condition. I was prepared for this question and prior to the interviews taking place I had sought advice from another researcher, and also from books on IPA. I decided that I would only disclose my diagnosis with those who directly asked about it and only after the interview had been completed. This meant that the focus of the interview was on the participant and not on me (Smith et al., 2009).

Initially, in designing the semi-structures interview schedule, I was aware that as the condition is chronic and incurable, that self-management would be an important aspect of living with the condition. Similarly, I was interested in the common sense model (CSM) of illness (Leventhal et al., 1980) and the concept of illness beliefs guided some of the questions that made up the schedule. Once the interviews had been completed, I was initially concerned that this prior influence on the question would have biased the analysis. However, each interview started with a broad question, 'can you give me a brief history of your story, from first experiencing symptoms to now', which allowed the women to give a completely undirected response.

Although the interviews were on average one hour long and many contained rich data, many contained a lot of descriptive data. Probing questions were used to further draw information from the participants; however, the questions asked sometimes focused on eliciting more descriptive details as opposed to eliciting the significance and the meaning of the experience for the woman. With hindsight, this would have provided a richer more experiential account of the condition.

Throughout the process, I found the act of keeping a reflexive diary invaluable. At times where I faced decisions about the analysis of the data, for example, organisation of thematic categories, the act of writing down the questions I had, along with the possible options, helped in clarifying exactly what was required to resolve the issue. In the event that I was still unsure about what to do, the diary helped me to formulate the questions I needed to take to my supervisor for further advice.

On a personal note I found the experience of carrying out the research project highly rewarding. The women were very keen to participate and have their story heard so that they may help other women in the same situation. Many also expressed gratitude that I was researching an area that had overtaken their lives, yet was felt to be neglected by the medical professionals and the general population. As a result, it has increased my interest in the condition as an area for future research.

Similarly, through researching the previous literature on the topic, I have come to question aspects of it which I had not considered before, such as whether there is a societal taboo around menstruation and women's health issues in general, and also the extent to which these issues affect my own life. The knowledge that I have gained from the women who participated in the study has also been a huge help to me in positively dealing with my own experiences of endometriosis, and for this I am very grateful.

5. Results

5.1 Participant's experiences of living with endometriosis – themes

The IPA analysis of the 12 transcripts resulted in five superordinate themes: making sense of the condition, impact on daily life, identity, taking back control and legitimisation. Within these overarching theme categories were further sub themes.

5.1.1 Making sense of the condition.

This super-ordinate theme had a high prevalence amongst the participants. Most women described experiencing symptoms and events which happened to them since those symptoms began through to the present day. Their descriptions can be interpreted as the process through which they became aware of a range of symptoms. In most cases these symptoms gradually got worse until the point where they sought help. An important part of the process was receiving a diagnosis and women described how this event helped them to understand what was happening to them and to possible causes. However, despite receiving a diagnosis, often the participants found themselves in a situation where they realised there was no cure for their condition and that they were left with unanswered questions.

5.1.1a Patterns and symptoms

This first subtheme centres on the participants' experiences of their symptoms. The women talked about noticing that patterns were forming in terms of symptoms they were experiencing. For example most of the women talked about having painful periods from the beginning and having pain at certain times of their monthly reproductive cycle, to the point that it had become normal for them

E1 - Initially I've always had really bad periods from when I was, I started periods at 11 years old, I've always had really painful periods up until I was 30 it became quite unmanageable. (p. 1)

E3 - Yeah, as I said it started off when I got my periods when I was like 15 erm 14, 15 and I always had bad period pains but it was always just when I had my period erm to such an extent that I actually got taken to the doctors by my mum because I was under the age of 16 and I got put on mycrogynon the pill. (p. 1)

E12 - It was kind of ovarian pain when I was first getting it, kind of stabby pains and then as I got older it became more dragging deep pains and now if I get endometrial pain, kind of from 25 onwards, I recognise what is ovarian cyst pain and I recognise what is adhesions on my cervix and what is the pulling pains, as well where things are tight. (p. 3)

However, although most noticed a pattern forming, some participants found that a difficult aspect of the symptoms was that there did not seem to be any particular pattern. For example, symptoms weren't always related to a specific time in their monthly cycle, or sometimes what they ate or drank made their symptoms worse, whereas other times they were ok. Although they may have symptoms each month, there did not seem to be consistency in the way the symptoms presented themselves

E9 - But there's no rhyme or reason to when it happens, no link to specific time in my cycle. (p. 3)

E1 - It happened quite a few times and there's no rhyme or reason to it at all. I can go out and have a good few drinks with friends and I can be absolutely fine and come home

be neither up nor down and then other times I have one drink or I'm just out I eat something and that's it, I go away the same vein passing out or being sick or whatever or just feeling as if I'm going to faint. (p. 18)

In both extracts here the phrase 'no rhyme or reason' gives a sense of the unpredictable nature of the symptoms, making it even more difficult to form an understanding of what was happening.

5.1.1b Gradual worsening of symptoms

As well as descriptions of the symptoms, most of the participants described how their symptoms changed over time, forming the second sub-theme. In general, symptoms that were manageable increased in severity, and became unmanageable

E12 - I started my periods when I was 12 and they were fairly easy but by the time I got to about 14 they started getting incredibly painful and with pain kind of around ovulation although I wouldn't have known what that was at the time... 2 weeks before and then erm I don't think I started to get bad pain with intercourse until I was about 18 or 19 but I started to think things maybe were wrong because the periods were getting worse and worse I was getting to the point where I was going to faint. Every month I was off school then I was off college and it was just quite tough. (p. 1)

E12 describes a common progression in symptoms, experiencing pain for longer periods of time and in different circumstances, such as during sexual activity, and to the point that it was interfering with daily activities

E1 – I went back and forward for 7 years erm with an array of symptoms that progressively the symptoms were getting worse and there was peripheral symptoms like digestive problems, bowel problems... I started to notice my skin wasn't as good, my

hair was falling out in clumps and that's why I always thought there was an underlying kind of hormone condition going on as well as just having problem periods. (p. 1)

In E1's case, the additional, seemingly unrelated health problems added to the deterioration of her health. Here it is almost as if she is 'playing detective' trying to piece all the elements together to make sense of what is happening, the result of which draws her to the conclusion her condition is hormone based.

In some cases, symptoms progressed to crisis point, for example

E9 - I got really bad pains and they were coming and going probably for about two months and they started to get worse and worse and I basically collapsed one day at work and got sent home. (p. 1)

E10 – And it wasn't the latter 4 years of that period I would say that what the pill did in the initial which was regulate the periods, make them not as heavy they weren't as sore. (The pill) had stopped working, I was getting pain for three weeks out of a 28 day cycle and it just seemed to get worse and worse and worse and worse, then unfortunately, just after Christmas I collapsed at my work and was rushed into hospital. (p. 1)

In both instances, symptoms got progressively worse until they resulted in the women collapsing and being admitted to hospital. E10 also adds to the sense of the increasing severity of the symptoms by her repetition of the word 'worse'. In many cases, despite having sought help from their doctors, it was only after symptoms had reached this dramatic level that referrals were made for further investigations to be carried out into the cause of the symptoms which led to a diagnosis. For others who had a more gradual progression, the change in what had been

long term symptoms prompted either more help seeking by the women, or a change in management from their doctors leading to a diagnosis of endometriosis.

5.1.1c Diagnosis

The third subtheme 'diagnosis' facilitated an increase in their understanding of their experiences, with just over half of the group talking about how the diagnosis helped them make sense of their symptoms

E10 – It's in pouch of douglas, my ovaries, my tubes, the ligaments at the back of my womb and now it's on my bowel as well, so it explains a lot of pain I'm getting which is good, at least I know where it's all coming from. (p. 5)

E13 - February 2009 and they found out that I had endometriosis in 2 locations; it was on my left ovary and in my pouch of douglas which would explain the bowel symptoms because it's so close to the bowel. (p. 3)

In general, the diagnosis helped the women to understand why they were in so much pain and the mechanisms behind the pain. The diagnosis gave the condition a name that they were able to research on their own. This increased their knowledge and it gave them a language that they could use to talk about the condition with others

E2 - I would say I probably feel better because it means now I can help myself. I can go to a support group you know, there's the forums on the internet and things if you just need erm that wee bit of help or so I think now that I know that's what I've got and I'm able to say it's a real thing, that that definitely I would say does make me feel better. (p. 28)

However, although the diagnosis helped them understand where the pain was coming from, it didn't always help them to understand what caused the condition. Despite several theories regarding the cause of endometriosis being postulated, so far a definitive answer has not been found. In some cases, these theories were a good fit and made sense in relation to the women's circumstances. For example, some identified with the genetic theory of endometriosis, as they had relatives that had either been diagnosed with the condition, or had similar symptoms or related gynaecological conditions

E4 - My sister's definitely got it, she got diagnosed with it...my mum's never diagnosed but when I look back at her, kind of you know when we were younger, I can see similarities. (p. 8)

For others however, there was not as good a fit between the theories and their circumstances, which led them to formulate their own hypotheses about what caused them to have the condition. Several theories were offered by the women, including hormones, viral infection, poor immune system, iron deficiency, having a caesarean section birth, and the initiation of a sexual relationship. However, despite having their own theories, most women acknowledged that they were only speculating and that they really did not know what caused them to have the disease

E13 - The only thing that we can think of is there's been a lowered immune system in myself and my aunt who's got the endometriosis...erm...she smoked heavily at the time but that was before they realized how bad it was. She smoked heavily and no one else in my family did and the polycystic ovarian syndrome, they have suggested is a part of lowered immune system, so it's the only things we can think of that has any correlation but whether we're making 2 and 2 and getting 5 is one thing, but we, it's a kind of what we've understood. (p. 11)

5.1.1d Barriers to making sense

The final part of the process of making sense of the condition, which formed the final subtheme 'barriers to sense making', was highlighted by half of the group. Here the women realised there was no cure and that the treatments to control the disease were not guaranteed to work. This almost signalled a barrier to further sense making, as they had to come to terms with the fact that the condition is chronic and that there may never be a resolution to their symptoms. For some people this was difficult emotionally to come to terms with

E1 – But what I didn't realised was that the treatment options are very limited so once you get your diagnosis you're full of hope that now they know what it is, they can deal with it, they can go and it's easy, especially in today's modern world where eh medics and science can do all sorts. You assume that there's so many things that can be done and it actually was, that's what I mean about the emotional rollercoaster, you went onto a high because you thought that's it finally diagnosed and then they were like "well we can only do this and this" and then you fall again, you think and then every time you have a treatment emotionally you feel this will work for me and when it doesn't it's very disappointing, then you move to the next thing and the next thing and the next thing until you've exhausted them all and there's not a huge list of them. (p. 25)

Here, E1 describes a constant and almost desperate search for a treatment that will resolve the symptoms. As well as having 'exhausted' all treatment options, there is a sense that she was also emotionally exhausted by this process.

Other women used phrases like 'double edged sword' and 'bitter sweet' to emphasise the frustrating situation of knowing what the condition was but not being able to do anything about it, and the irony that the surgical treatments used to alleviate the pain, could lead to more pain by increasing scar tissue

E3 – The more scar tissue you get the worse it gets you know, I mean they did say at the pain clinic it's like a double edged sword, there's no way to actually cure there's no way to cure it. The only way they can try and treat it is by either using medication or by going in and operating but the more they operate the worse it gets you know. (p. 7)

E4 - It's a weird thing isn't it, its bitter sweet isn't it? It's like being told you've got a diagnosis of something that we don't know a lot about and we can't cure it. (p. 10)

In general, the women moved through a long process of trying to make sense of what was happening to them, from the beginning when they had painful periods, the condition getting progressively worse until they were in a situation where they knew what the disease was called and the reason for their symptoms. However, this process halted as the women were faced with an uncertain future living with endometriosis due to lack of successful treatment options.

This process of trying to make sense is common across most chronic conditions and has been analysed in depth. For example, Bury (1982), in a study of the field of rheumatoid arthritis, suggests that chronic illness is a 'critical situation' which he defines as a type of 'biological disruption'. The women in this study support his assertion that one aspect of this disruption is the 'disruption of taken for granted assumptions'. Here, the women's focus on noticing patterns and symptoms signifies the first stage of the disruption, where those with the chronic illness begin to notice and recognise different 'bodily states' as signs of potential illness. Similarly, looking to their own local and familial knowledge and experience for a cause of their condition is suggestive of his second aspect of disruption, the 'disruption in explanatory systems' leading to a 'rethinking of biography and self-concept' where the women's expectations of the medical system to be able to explain and successfully treat their condition are not supported (Bury, 1982 p.169).

The way the women looked for the cause of their condition by relating it to their own knowledge, their own context and also to family members that suffered similar symptoms, supports the common sense model of illness (CSM)(Leventhal et al., 1980). However, this model suggests that the identification of the cause of the symptoms (as well as the other four types of illness representations) will have implications for the coping actions the individual will take in response to the symptoms. The Theory of Cognitive Appraisal (TCA)(Taylor, 1983) however, goes further and suggests that the actual causal attribution applied to the condition is not important, it is the causal meaning that is most important. Similarly, Taylor suggests that meaning is found from considering what the condition means for their life now. In this study, the women are left with uncertainty about their future life due to the lack of a cure and of treatment options.

The next theme, which follows on from making sense, is the impact of the condition on daily life.

5.1.2 Impact on Daily Life

This theme was highly prevalent with every participant discussing at length how the condition interfered with their daily lives on three levels: the disruption and interference with daily life, being controlled by 'endo', and the psychological impact this had on them.

5.1.2a Disruption

For this first subtheme 'disruption', the women described high levels of pain and fatigue, as well as other gastrointestinal and digestive symptoms experienced, which meant that most areas of their lives were impacted by the condition

E1 - Then it got to the point where you just couldn't function erm with a period. It wasn't just during the period it was before, during and after and it started to impact on your ability to do things and work and socialise and different things. (p. 1)

E2 - So then I was still really exhausted, I could never really just get over that tiredness. Every single day was just like, I couldn't even describe how hard it was to get up and out of bed and get to work it was just... that in itself was exhausting and then I'd be at work and be completely exhausted trying to do a really busy job. (p. 4)

As both women highlight, work was a part of their lives which was disrupted by the condition. From the women's transcripts, there was a sense that, for various reasons, maintaining a normal working life was a priority despite the fact that often the pain made it impossible to fully engage in their work responsibilities

E5 - There was points where I mean, I have to be honest, if I was my boss I would have sent me home because I looked like death warmed up so, a nice grey green colour and I mean I was in agony. (p. 12)

E8 - In terms of work, I just try and struggle through it. I've been there three and a half months now and I've had sore stomachs but I'm too busy to take the day off to be honest with you and I just...I travel with a hot water bottle (laughs). I do...which sounds quite ridiculous but I do and that, I just do it that way sometimes...sometimes you can't you're just sitting there and that's all, you just want to go home but it's not always possible. I would say I'm trying not to let it affect my work just because of my traineeship is really important just to get it done. (p. 11)

E8 also talks about the added pressure of a lack of job security making it even more important to maintain as normal a working life as possible, which was echoed by some of the other women

E8 - I think I could let it affect it, you know, I think you could easily go down the line of I think if I took one day off now I would in future if I had a sore stomach, oh 'I'll just not go in today' because it does help not going in and resting. It does help but it's not really possible. I'm based between two offices just now, I'm kind of, they used to take two trainees on to do and they've just got one this year just because of how everyone is erm so if I do that the boss will be waiting on me when I come back in. (p. 12)

Financial issues also meant it was impossible for the women to take the time off that they needed and risk losing their jobs

E4 - I literally did my job because I needed to pay my bills. (p. 11)

E13 – I'll say I've had very few days off work due to endometriosis purely because I just go and I'm stubborn. I'll just go into work no matter what you know. I probably shouldn't but I do and this they're making redundancies and things at my work so you do what you can to get your to keep your job. (p. 10)

E5 tells of the financial implications to her and her family from having to adapt her working pattern to accommodate her condition

E5 - I've gone from you know being sort of quite a confident you know, I was basically associate director of my practice, you know career orientated. I after my surgery and that I couldn't go back full time erm basically just physically I couldn't like, we work like 12 days and that you work like Monday to Friday then you've got the Saturday Sunday then you work Monday to Friday the following week I was just like I can't do that, I just can't do that erm so financially it's had a big impact you know. (p. 15)

The pressure felt by the women to go to work had a knock on effect on the rest of their lives. Many participants described how the fatigue they experienced was so debilitating that they had no energy left for any other activities once they came home from work

E1 – But in between times, when all this was going on, I really had a lot of difficulties at home because you were just very, you were just chronically ill. I struggled to work... I was so chronically tired that all I could do was fulfil my work obligations but I couldn't do anything else. (p. 6)

Lack of energy and pain symptoms also interfered with their social life, where meeting up with friends and family and enjoying pleasurable activities were no longer possible

E4 - It affects everything. You don't go out with your pals, you do what you have to do a lot of the time and that wasn't even going to like shopping round the shops you know Asda and stuff like that. I was literally, I would do a lot more groceries online. All my Christmas all the things that I enjoy doing, I just I couldn't do them because I was in too much pain or too tired with the fatigue all the time. (p. 12)

E5 - I can't go back to Edinburgh and go out and things like that the way I would like to. I can't stay in contact with the friends that I had over there and stuff. I would like to but because of the fact that I don't I just don't have the energy I can't drive over there and go out for a couple of hours and drive back I'm floored for two days afterwards. (p. 23)

E7 - It did affect my social life cause you would go out for dinner and you would be in the bathroom and you would be in pain or you would have an upset stomach and it was all the time and I was always conscious of it and then I would have to say 'home now' again and erm so yeah it definitely did affect it. (p. 10)

E4's comment, 'you do what you have to do' illustrates the idea that the women feel they have to prioritise their activities in relation to what they are able to manage, which means that sociable activities are often the first to be sacrificed. Those who suffered the symptoms from adolescence reported their school life being disrupted by the pain. In addition, due to having heavy periods, some women also experienced 'flooding', where blood would leak through their sanitary protection

E6 - There's also like experiences of, oh this is horrible, really heavy periods throughout teenager like teenage, so there would be points where I'd be wearing a tampon and a pad and without even knowing I'd like have quite a few friends looking out for me and I'd have blood all over my jeans so I had like to carry a spare pack of like trousers and pants. Both my brothers were trained all the way through high school that if they got a phone call it would just be pants and a pad in a bag and bring it to me. (p. 3)

E7 – Painful periods from really when my periods started. They were extremely heavy I mean I would sit in a classroom within an hour of, you know, putting fresh tampons or towels whatever at that time, I could have a pool of blood around me on the floor. (p. 1)

In other cases, the pain was bad enough to affect their mobility

E3 - In the past wee while, the past few weeks, it's started to affect the way that I walk at times because it's sore, in particularly, in my right leg so it makes me kind of limp a little bit and in my groin erm which I've never had before so I'm assuming that's the chronic pain. (p. 6)

E12 - At period time, it was just that wave of horrific pain and then it's obviously in the sciatic area as well during period times and ovulation times. I've been at the point where

I've not been able to walk for weeks on end because it's it's somewhere near the nerve and it's shooting down the legs. It's like I've done my back my backs gone out like a slipped disc but it's not a slipped disc. (p. 4)

E13 - Then the pain started again erm and that's when I had to start using the stick cause it had got so bad. (p. 4)

In addition to the direct impact of the symptoms, the medication that many women took to try and control the pain also interfered with daily life. In some cases, extremely strong painkillers were used to enable them to carry out the daily activities that they had to do. However, these painkillers, such as morphine would, for example, limit their ability to drive. In other cases, the drugs would make them drowsy or sleepy, so that in fact they would not be able to do anything at all

E4 - I literally used to do my job and then come home and cause obviously I was wearing the morphine patch, I would only wear a lower dose to be driving, and then I'd come home and take the bigger dose to take the pain away, so I would literally just be like lying on the couch. I just used to lie on the couch all the time with a hot water bottle or up in my bed watching DVDs and sitting on the laptop all the time. (p. 11)

E10 - When I was really bad a few months back and I was on numerous pain killers and I mean I was taking morphine and stuff and obviously if you take that you can't drive, you're out your head most of the time so you can't really concentrate at work and stuff so but it's a necessary evil if you like, cause you need to take it cause it's the only thing that makes it bearable to be out of bed and all the rest of it. (p. 17)

E10 describes her pain medication as a 'necessary evil', which almost implies a sense of injustice whereby the medication that is supposed to help is actually just as 'evil' as the condition itself. However, the slight benefits brought by the medication marginally outweigh their detrimental effects.

5.1.2b Controlled by Endometriosis

In each of these examples, there is a sense that every aspect of normal life has been altered by the symptoms of the condition. The women take this notion of the disrupted life further in the second theme and talk about how it has actually taken over their lives completely, to the extent that many felt completely controlled by the condition. For example, a common experience was not being able to plan activities in advance, or having to plan their life around their monthly cycle

E7 - The pain was always there. I had to kind of fit my life around my periods. If I was going to have a period it would be a kind of housebound kind of weekend, one because it was heavy so I was always scared of flooding everywhere and being uncomfortable and embarrassed and the pain was just unbearable. (It) carried on like that and for years and years and years (p. 1)

During her period, E7 was trapped both by the physical aspects of the pain and flooding and by the psychological impact where the fear of these things happening made her not want to leave her house. Her repetition of the words 'for years and years and years' gives a sense of the length of time she has felt controlled in this way

E9 – So it's kind of planning a lot of my life around it is how it works, like planning going 'right I'm doing this, I'll be out for an hour, come back, I can take a painkiller' then cause if I need to take a tramadol I can't go out I can't drive so...I went carpet shopping with my mother-in-law for new carpets and I said 'right (name of town) an hour, fine come

back take it' and it didn't work that way. We ended up bumping into (boyfriend) and going straight to the supermarket and I nearly cried in the supermarket it was that sore, so it's just become all controlling of my life. (p. 7)

Here, E9 describes that despite her attempts to control the condition and live a normal life by attempting to do everyday things, these attempts do not always go to plan and can be easily derailed resulting in an escalation of symptoms. As well as planning day to day activities, E9 also expressed how she is planning her future around the condition

E9 - I'm actually timing my whole of my next year of my life around this op like, I need to get a job and start in January, I could probably get 12 months working without like that bothering me and then my boyfriend and I decided we'll try for kids and then hope I have kids and that should, so I'm having to plan my whole life. (p. 7)

This restrictive aspect of chronic illness, such as not being able to work and the effects of medication are discussed by Charmaz (1983). In this study, the restrictions that chronic illness place on life are seen to result in a loss of self, where the restrictions lead to social isolation and opportunities for a valued self to be constructed and maintained. In addition, the Charmaz study also highlights that sometimes individual's themselves place unnecessary restrictions upon their lives by failing to question and challenge the environment and systems which are designed for 'healthy' people. In the present study, the women's lives were indeed restricted by both the condition and the medication they took to manage the pain and may explain why the women made such efforts to maintain their working lives despite leaving them too fatigued to engage in other social activities. By prioritising their work, the women were placing restrictions upon themselves in other areas of their lives. Similarly, the women would remove themselves from social and valued situations due to the embarrassing nature of the condition. Ultimately, Charmaz suggests that the experience of living a restrictive life caused by chronic illness leads

the ill person receiving images of themselves which are counter to their existing sense of self. This loss of self is seen by Charmaz to be the source of suffering in the chronically ill, and is relevant to other themes which are discussed later in the present study.

5.1.2c Psychological impact

In the final subtheme, the women spoke about the psychological impact of living with the condition day to day. The level of psychological adjustment in the group varied; however all but one participant indicated some form of negative psychological reaction to the disease.

One common negative response was the experience of worry or anxiety about the future. The lack of an established cause and cure for the disease meant that the women live with uncertainty about how the condition will affect their future. Those who were currently managing their pain were aware that their symptoms could escalate at any point. There is a sense of anxiety over the pain re-occurring in these women and of not being able to cope if that happened

E2 – You know it was really...erm...I, I never want to go back to that. I don't think I could go back to that pain. (p. 10)

E2 later repeats this sentiment but this time emphasises how desperate the pain made her feel

E2 - I could never go back to that pain. Never, I mean...I know this is a bit extreme, but if you'd have gave me a gun at the worst pain, I probably would have shot myself. (p. 34)

Both E4 and E6 also highlight how their anxiety is centred on not only the impact on their own lives but also on the lives of those around them

E4 - When I look back at that I sometimes think oh my god I hope I never go back. I have a fear of ever going back to that to be honest with you, cause it was a difficult time not just for me but for my partner as well and fortunately he, he was very understanding of it but it did cause a lot of, you know, challenges you know with us. (p. 11)

E6 - I just hope that I never ever get to the same point that I was at before, like the symptoms don't come back, erm, because I don't think I could live with it day to day again especially not with the mood swings. I don't think anyone would want to live with me again erm and I think you know, I just don't think I could. I think I'd rather get it all removed as much as possible and I know there are symptoms that still linger on after you have had had everything removed. I just hope that it never comes back. (p. 17)

For two women, daily anxiety was caused by the knowledge that they could do nothing to control what the disease was doing inside their bodies

E3 - You do feel quite a bit of the time that you don't have any control. You don't have any control over how often it grows....but sometimes you do feel that you're not in control of anything so as I say you're not in control of how quickly its growing you're not in control of the pain or anything like that. (p. 18)

E10 takes this further where she likens the disease to some kind of malevolent entity or alien that is taking over her body, which she has no control or power over. This is emphasised by her use of the words 'slowly creeping' and 'just waiting to pounce'

E10 - So it's just almost like every time I go back into see my consultant it's like another thing that's added onto the list 'oh that's what's causing that' and you're like 'how much

more is it going to cause'. It just seems to be slowly creeping throughout my body and I think... just, just stop. (p. 19)

E10 – It's just a constant daily struggle with something inside and you don't know, has it started already or is it just waiting to pounce? It's just like, I can't really describe how it makes you feel, it just kind of makes you feel like someone's inside stabbing at you but nobody else can see it. (p. 3)

As well as anxiety, many women reported feeling a sense of hopelessness and depression about their current situation and also the future. The lack of treatment options and no hope for a cure meant that the participants were faced with a future of continuing or even worsening pain. Some of the women had suffered from depression in the past and their endometriosis may have contributed towards this as it is a recognised symptom of the condition

E4 - The frustration that you get and sometimes you get angry that you've got something and nobody knows what it is really and they can't tell you what it is, what's caused it and how they're going to fix it. You sometimes feel a bit, this is quite, you can feel despair sometimes. I spoke to my sister about it you know, you sometimes feel that your just...you're just different from other people cause you've got this. (p. 21)

E8 - I don't know, just fed up really and in terms of the future erm I don't know. I don't see there being anything happening anything soon in terms of research. (p. 19)

E12 - I was finding that every month I was in a really deep low when my period came, to the point where I couldn't cope with it and I just, it just affects you so badly. You get two, you get two weeks after that and like 'oh god I feel better' and then the pms starts all over again. It's an awful cycle. (p. 10)

Feelings of anxiety were heightened by the impact the disease had on the women's fertility. For those women who wanted to have children in the future, worries about whether they would be able to or even when to start trying to conceive dominated their thinking

E4 - It puts a lot more pressure on just trying to make a decision can we afford or do we want to have another kid. There's a lot of other stuff but emotionally I think if I go and find out that I can't have any more, I'm quite worried about how I'm going to go at that point. I think I'll just be devastated for them to tell me that I can't and we can't put it off. We've kind of not faced it yet cause we weren't ready. (p. 20)

E9 - I often think about the future and two of my friends have had kids recently and one's pregnant and I go 'what happens if I never have that?' That's my fear about how it will affect my future is it's just the thought about never being able to have a kid it doesn't go down well. I think that's my main fear as regards to the future. (p. 11)

In Leventhal's common sense model of illness, as well as recognition of the cognitive responses to an illness, there is also an acknowledgement of the emotional responses generated by these cognitive responses. The lack of cause, cure/control and consequence representations that can be formed due to the nature of the condition may explain the women's negative psychological response to the condition.

Another psychological response to living with the condition was a sense of loneliness. This seemed to be due to the lack of knowledge and understanding about the condition even among medical professionals. As a result, the women felt isolated and would stop talking about how they felt as they had to repeatedly explain to people what was wrong with them. In addition, many women talked about how they had lost friends since having the disease because they

weren't able to socialise. Sometimes this was due to a conscious removal of themselves from their social circle due to their pain and levels of fatigue

E1 - You start to remove yourself so you're turning down invitations all the time, and then eventually people don't want to invite you because you're just not going. (p. 18)

E4 - I was getting to the point you know, you're disassociated....I've lost a few friends over, you know in a couple of years, because well I thought they were friends but because you weren't going out to the social events and the drinking and the partying and the dinners all the time they kind of lose you a wee bit so that's quite you know hurtful as well cause you always felt people were just thinking you were making excuses you didn't want to go out and you would love to have gone but you couldn't have. You couldn't stand in a pub with that pain. You couldn't even sit in a bar, sit in a restaurant, you couldn't eat because you'd be in the toilet all night in pain, so erm it does affect you mentally. (p. 13)

E10 – How do you deal with friends that suddenly fall off the radar because... you're...you can't go out all the time and that has happened to me. I used to have a huge wide circle of friends. I now have a small circle of friends who are some of the best friends I think a person could ever have but I had a lot more but they've all dwindled away and it's fair enough. You think, well they weren't really that much of a friend in the first place if that happens which is fine but at the time you think well 'why do people not want to talk to me anymore?' and then you start thinking 'is it because I can't go and do this?' like as I say, you can't plan in advance holidays or things like that cause you just never know how you're going to feel. (p. 34)

In general, the women who had experienced 'falling out' of their social circles appeared to be philosophical about this, almost accepting that people would not want to be friends with them

when they were unable to take part in social activities. Both E4 and E10's extracts suggests that the women themselves feel they are somehow to blame for the loss of their friendships, which could explain their acceptance of their social isolation.

Social isolation has also been highlighted by Charmaz (1983) as a consequence of living a restricted life and was related to being discredited, ignored and devalued by others and is seen as another source of suffering in those with a long term condition. Similarly, Bury (1982) also highlights social isolation as a disruption to taken for granted experiences of friendship and community relationships.

Some of the women who experienced pain during sexual intercourse talked about the psychological impact this pain had on their sexual relationships. Two women, E9 and E12 spoke about how they had developed almost a phobic reaction to having sex. Even when they were not in pain, the association that had formed between pain and sex meant that they were afraid to engage in sexual activity for fear of the pain returning

E9 – Which is just...yeah...erm I can't have sex when I'm sore...but I'm scared to have sex when I'm not sore in case it hurts which psycho...you know psychologically, its affected that. (p. 6)

E12 - We've been together 10 years now this month and married just a year and a half but it's been awful that it affects our sex life still because there's a fear of hurting me and I've not had pain with sex for about 2 years now but we both have that phobia. (p. 5)

Finally, another psychological response to the condition was anger. This again came from the lack of research and knowledge about the condition leading to frustration

E10 - There's no, as I say, there's just nothing, nobody you can go out and talk to all these things about and that's...frustrating very frustrating. I think I probably spend 99% of the time angry at this condition. Very, very, very angry and that in itself isn't healthy to have a lot of...anger and aggression inside you and it's hard. (p. 22)

However, in one participant's case, her extreme anger responses may have been more directly related to the hormonal influence of the condition. For E6, the out of character verbal and sometimes physical aggression was a major feature of her experience of endometriosis. Although she mainly vented these aggressive feeling at her family members, she tells of being scared of the thoughts she would have about people

E6 – 'How can you not understand this...your breathing is just the loudest breathing that I've ever heard and you need to control it because I'm that I will kill you' erm...and those are very scary thoughts to have so usually...my dad got it quite a bit actually, bless his heart. Like at the height of it all, like usually I was bleeding, I'd be like 'you fucking arsehole for giving me like the xy chromosome that made me female' cause I was just and he would just sit there and take it all which was quite good cause I suppose I could just get it all out. Then it'd turn to tears and then I'd manage to at, that point the pain usually subsided cause I'd taken enough tablets, had a little cry then go to sleep and sleep through it all. So yeah the moods and the aggression was probably the worst part of it all (p. 10)

It is clear that endometriosis has wide reaching implications in terms of interference with daily life. However, the impact of endometriosis not only had an impact on what the participants felt was happening to them, it also changed the way they saw themselves, which forms the basis of the next theme, 'identity'.

5.1.3 Identity

Throughout the process of living with endometriosis, participants frequently talked about issues which suggested that their condition had a profound impact on their sense of identity.

5.1.3a Questioning self

In the first sub theme, several of the women in the group described periods of self-doubt where they questioned their own perceptions of themselves as an individual and their sense of reality in relation to the symptoms they were experiencing. For many, the isolation discussed in the previous section and lack of awareness of the condition meant that there was little opportunity to compare their symptoms with those of other people in a similar situation. In addition, all of the women in this study had experienced negative responses from the medical profession, which at times, called into question whether their symptoms were as bad as they reported. This lack of legitimisation will be discussed further in the wider sense of the medical and public view of endometriosis. However, for these women, having their symptoms doubted and being isolated, resulted in them questioning whether others were correct and that they were either imagining the pain, or exaggerating it. Their view of themselves as rational beings was being challenged

E13 - I was still recovering from my laparoscopy at this point and I was in a lot of pain and they just... 'it's all in your head'...there's only so often you can hear that before you start to believe it. (p. 17)

E4 - You start to actually look at yourself and go I'm scared to go back to the doctor because they must think I'm going off my head cause I'm literally going back with this is something else happening to me and is this something else, but fortunately they've known me before and known that I was not a bother patient, you know, not a patient that really bothered with them erm and then, I've gone from that to kind of ill health, ill health,

ill health. So I was quite lucky they weren't kind of thinking she's just off her head, but it's quite easy to start thinking 'am I just not coping is it just me?' and its slightly weird.
(p. 10)

E1 - But even in the medical profession it lacked credibility so I think that's what made it psychologically difficult to deal with because they diminished it all the time and you actually thought I'm really over reacting to something that's obviously not a big problem.
(p. 21)

E4's extract highlighted how she felt lucky that her doctor knew her before her symptoms escalated as she didn't have to prove to them that her symptoms were real. However, despite knowing this, it did not stop her from doubting herself and questioning whether she was actually in a severe amount of pain, or whether other people experienced this but managed to cope with it. When she says 'am I just not coping is it just me?', it suggests that she sees herself as someone who is strong and who can cope, but that this is called into question by the suggestion that other people cope with this and that she is somehow weak.

Charmaz (1983) highlighted this as a form of discreditation which can lead to a loss of sense of self. She also suggests that the impact of the discreditation will be greater under certain conditions, two of which being the importance of the person doing the discrediting and how many times it occurs. In the case of many of the women in this study, the fact that medical professionals were repeatedly dismissing the women's claims suggests that this form of discreditation may have had an important impact on the women's sense of self.

5.1.3b Changes to identity

As well as placing doubt in their minds about their actual experiences of the pain, and even about their sanity, living with endometriosis changed the way the women saw themselves in several other ways, forming the second sub theme, 'changes to identity'.

For example, due to the impact of the disease on their daily lives, many women felt that they were not able to perform the social roles that they themselves and others expected of them. These roles included the role of wife/partner in both a sexual and non-sexual context and the role of mother

E1 - And to be perfectly honest, you know, there were times where my job, my social life, your relationships were hanging by a thread because you just were...you know, you couldn't be what you were supposed to be to anybody and I think that's quite a difficult thing psychologically to live with, that you're not up for doing things that your friends want to do. You're not really able to fulfil a full relationship because you just...you actually become quite self-obsessed because you can't think of anything else. All you can think of is how ill you feel all the time. (p. 20)

E4 - How that affected me was I literally just, I wasn't, I felt I wasn't a good mum because I couldn't really do an awful lot with my wee boy. I wasn't a good partner, I mean physically, you just could not have any kind of sexual intercourse whatsoever, it was just horrendously painful. (p. 11)

E4 - For me as a new mum, I felt you know, god I've lost a lot of my wee boys first few months of the things I would like to do, so I felt a bit of a failure there. You don't feel, you feel a failure as a partner, you know the physical side, and then you're just not fun anymore. So it does, I would say it really affects you mentally. (p. 13)

In these extracts, there was a sense that not being able to carry out roles as a partner and a mother meant that they were in some way less of a woman, undermining their sense of what it is to be female.

The word 'failure' was used by several women when they described how they viewed themselves implying that fundamental goals had not been achieved due to the condition. Similarly, the phrase 'couldn't function' (e.g. E1, p. 1) was used more than once, suggesting that the women felt that they were not able to carry out automatic or basic activities, which again challenged their view of themselves as useful individuals.

The notion of 'discreditation' as a source of loss of self (Charmaz, 1983) is also relevant here, as the study highlights one source of discreditation comes from the person themselves. Here, as the person views themselves as failing to live up to their own high standards, they judge themselves as having less value than others. Charmaz also suggests that discrediting definitions will be more likely to be accepted when the individual is vulnerable, if they identify with the person doing the discrediting or if it 'validates a hidden fear'. In the present study, the women are already vulnerable, and they talk about very personal and significant fears, such as being a failure as a sexual partner and as a mother. In this sense it is easy to understand why the women see themselves differently and in a negative way.

For E10, this sense of being less of a woman was also related to her physical identity, where the hormonal effects of the condition and the subsequent hormone treatments she received had changed her body shape to the extent that she no longer felt feminine

E10 - At the moment, I would say that I feel less of a woman this time round. The disease has caused me to lose an awful, awful lot of weight. I've put it back on now slowly but my body shape's changed dramatically. Now my boyfriend laughs, he says

'you know how many women would kill to lose this amount of weight' he says honestly and I'm like 'yeah that's fine but I don't'. I was happy being the size I was and I like being a wee bit cuddly if you like and I liked having curves and my hips and they're coming back now but at the time they were kind of like, I don't want to look like this and I didn't feel womanly and I didn't feel attractive. (p. 21)

She also goes on to say

E10 - I think that...again it's in my head, that's how I feel when I look in the mirror. I don't see what my boyfriend sees, well I don't think I do, I think he sees whatever it is he sees but I don't see that, I don't see a nice attractive girl, I just see... I don't know what I see, I just see darkness. I just don't feel like a woman at all. It's like I don't have, I don't the tools in me to be a woman at all, you know maybe that is cause you've got no oestrogen so maybe you are just starved of all female things but... I think that's quite difficult and I think if I had a hysterectomy, does that take away everything that makes me a woman? Like the classical description of what being a woman is, you know is that taking all of that away? Then I think, can I live like that? (p. 21)

E12 also echoed the sense that she felt less feminine due to the condition, a view that was linked to the effect of the disease on her body image and her sexuality

E12 – It's affected my self-esteem massively. Like I live in jeans, I still live in jeans. I started wearing dresses a few days ago and that really is a symbol for me that I'm starting to feel better about myself but yeah you just kind of hide your body or you, especially if you're not sexually active or if you're feeling bad about it, you just don't want to be sexy because you don't feel it and you just feel pretty ugly. I feel a lot better now but I've still got a long way to go. (p. 11)

As in E10's excerpt above, for those women who were facing the possibility of requiring a hysterectomy in the future, the idea that removing these particular organs would make you less of a woman was raised. However in this group, this was not always supported, where some women who did not want to have a family were less likely to associate a hysterectomy with a challenge to their female identity. This was illustrated by the excerpt from E1, who had accepted that she would not have a family and had requested to have a hysterectomy several times

E1 - People used to say 'oh you'll not feel like a woman' and I thought it's the most ridiculous statement, you've got no sense of what's in there at the beginning so if you're missing a bit or two you're not going to feel any different., I don't feel any different than I did before at all but I was very both physically and psychologically ready to have that operation. I couldn't have cared less what organs they removed if it had stopped that pain, so my desire to be pain free outweighed not having a hysterectomy. (p. 33)

And despite the worries that having a hysterectomy would make her less of a woman in the traditional sense, earlier in her interview, E10 appeared to be more objective in her thoughts about a hysterectomy

E10 - At the moment my decisions that I'm trying to come to terms with now is where do I go from here? I'm going to be 35 in 2 days' time, I'm not getting any younger, I don't, don't really need a family to fulfil my life, so is there any point in hanging onto stuff that no longer works? (p. 5)

Other ways in which the women felt their sense of identity was challenged included changes in their emotions, for example, being aggressive when they didn't see themselves as an aggressive person

E6 - It was really hard to tell when you're angry because you're angry or whether it was the hormones making you angry and that was my biggest hoo-ha cause generally I'm not, I'm quite a chilled out person. Like things pee me off but at that time I couldn't tell you what was pissing me off or what was just my hormones going mental. (p. 6)

Also being seen as someone who shirks their responsibilities towards work and other people, when they saw themselves as hard working, conscientious and reliable

E2 - It doesn't even sound like that's me cause I've basically worked my whole life. (p. 4)

E12 – And I'm such a hard worker. That was really hard thing for me to take. I think it's very common. (p. 5)

Likewise, women started seeing themselves in general as boring, or 'no fun'

E13 - I feel like I'm ancient (laughs) and I should be, you know, 25 I should be going doing fun things. (p. 13)

5.1.3c Masking reality – trying to maintain identity

In what could be seen as an attempt to stop these challenges to their identity occurring, many women reported not being completely honest about the effect the disease was having on them or the full extent of their symptoms. Instead they chose to 'put a brave face on it' and carry on as usual, forming the final subtheme, 'masking reality – trying to maintain identity'

E3 - It stops me at times from wanting to go out. It stops me wanting to go and see friends because you know, you do put a face on it, you do smile, you do just say 'oh

yeah I'm fine I'm in a bit of pain I'm fine', cause you don't want to moan everyday as well you know erm but it does have a huge impact. (p. 10)

E4 - You actually worry that you're just becoming a moany person because if somebody says to you 'how are you?', if you told them truthfully how you felt you had to just keep saying 'I'm fine' but really inside you're like 'I'm in agony but I'm not going to tell you that cause you don't really want to know'. So you're worried that you're becoming just a bit boring and moany, you know which was different from the type of person I had been before. (p. 14)

These extracts suggest the reason for hiding the true nature of their experiences is a fear of being judged negatively by others. Women were caught between wanting and not wanting to tell others about the full extent of their symptoms, as they felt they would be viewed as someone who complains a lot and this was something the women went to great lengths to avoid. It is possible that their decision not to tell people how bad things were was also due to previous responses they had received when revealing the extent of their symptoms. For example, E13 talks about being aware of negative responses from her employers which shaped the way she hid the condition from others

E13 - My new boss is a man and his deputy has made comments about somebody who has problems with their periods, 'aw I don't see why what they're problems are they should just come into work you know it's only your periods', and I'm just well, so I've not told them. (p. 10)

E7 also played down the significance and impact of her symptoms to her husband on the basis of his reaction to her symptoms

E7 - Because men are men, they can only so sympathy for so long and to be honest (her husband's) one of these guys unless blood guts and you require an ambulance the sympathy's not there, especially when its every day, erm so you kind of learn to, you actually do suffer a lot more and don't say much about it and say ok you've got a sore stomach or erm but yeah I would only really say if it was I'm really, really bad and when I'd to go home. (p. 10)

E1 also described how, even when describing her symptoms to her doctor, she would hold back on the full extent of her pain

E1 – Again, you don't want to be over dramatic and you're saying I was on my hands and knees I couldn't stand up and you're having them look at you as if 'oh my god what a hypochondriac' so there's always that at the back of your mind I think, you're always very aware of what you tell people. (p. 34)

The changes to the women's sense of self and identity may be explained by the view that identity is a social phenomenon and is constructed depending on the context in which the person finds themselves. Culturally in the UK, it remains that when people are diagnosed with an acute illness they are 'allowed' to relinquish their responsibilities until they are well again as long as they demonstrate the will to return to health as soon as possible (Parsons, 1951). However, in chronic illness, as there may be no 'returning to health', the sick role is not so easily accepted by 'healthy' people. In the case of the women in this study, they had already received negative responses from others, and therefore made great efforts not to adopt the 'sick role'. Another reason why the women may be keen to hide the extent of their condition and normalise their symptoms is highlighted by Radley and Billig (1996). They suggest that if the sick role is adopted too easily, there is a danger of being labelled as 'weak', a judgement which has implications for the individual's credibility in other areas of life. However, the problem the

women have here is that by avoiding adopting the sick role too easily and being 'a good patient', they run the risk of their condition being viewed as less severe than it actually is. As can be seen in these excerpts above, this moral aspect of illness and feeling the need to normalise symptoms has implications for the women's willingness to seek help from others, such as employers and doctors as they choose who to disclose their condition to and whether to disclose the full extent of their condition.

Hiding their symptoms from others due to receiving negative or dismissive responses is related to the fifth and final theme 'legitimation' and is discussed in section 5.1.5. However, after discussing the impact the condition had on their lives and on their identity, most women were also keen to talk about how they attempted to cope with the condition, which is discussed in the next section.

5.1.4 Taking Back Control

5.1.4a Coping triggers

As has been discussed previously, many women felt that their condition deteriorated to the point where their symptoms were no longer manageable and were taking over their lives. At this point, many women talked about reaching a stage where they realised they had to try and take back the control they felt they had lost over their lives. In the first of the two sub themes, 'coping triggers', the women expressed different reasons for deciding to take back control. However, most of them involved a realisation that they could no longer live as they were and that things had to change.

E7 – (My husband) and I went to Milan and I was sitting in a restaurant doubled up in pain and it helped to walk, so we were wandering about, tears streaming down my eyes

in Milan and I just thought this is ridiculous; I'm mid-thirties and I shouldn't be like this.

(p. 2)

For E3, the trigger was realising that she had actually reached a state of acceptance that she would have pain, and that operations would help relieve her pain for a while but that it would return. However, a change in her job and a rapid, dramatic increase in her pain levels meant that she was not able to manage in the way she had done in the past

E3 - I think the fact that I think I'd grown, not accustomed to, but I'd kind of accepted 'right, have an operation, a year to a year and a half pain free' kind of, then it kind of kicks in but not as bad as what it's ever been, as I said, as what is just now. It was always...it was really painful but it was always manageable pain to a certain extent erm and I don't know whether that's maybe because of the job I was doing as well, I could kind of say, well you know, I was able to take it a little more easily. I don't know if that's anything to do with it but I then you know, obviously I went to the pain clinic. I was taken completely taken by surprise when this pain kicks in six weeks after my operation. So taken by surprise and it really actually quite got to me. I thought I'm back at bloody square one. Why am I back at square one again? (p. 19)

E3 - I think if I'm really quite honest, I'd kind of grown to accept that I was going to go through that type of a pattern but then it all changed and I thought I can't live my life like this. (p. 19)

For her, attending a specialist pain clinic supported her in making changes to her lifestyle which made her feel more in control of her own health

E3 - Going to the pain clinic, I think that was a huge changing point of me taking control back again and I think control is very important in your life no matter what situation you're in. If you have a bit of control over it you feel as though you've got some sort of impact and some sort of say on what's going on, so I think that that's, I think that that's been very important to me. (p. 25)

Other women highlighted that a sense of frustration and hopelessness about further treatment options or lack of them, made them more determined to find their own ways of coping with the condition

E12 - The symptoms came back horrifically and I just thought I cannot live like this so I researched things myself since they, I don't know, they were talking about putting me back on the the loestren is it loestren?... No prostap injections that I'd had when I was 27, which I had a very bad reaction to and I just didn't want to go down that route. (p. 2)

E8 - I guess the frustration and the disappointment and the nothing out there is putting is putting my thoughts towards an alternative form of treatment. (p. 20)

E10 also believed a more settled personal life in general as well as a lack of treatment options led her to change her attitude to the condition

E10 – I think it was erm the last, last August September I felt my symptoms coming back on and when I went back to see my doctor then, eh he just put me on a progesterone only pill to see if we could just even buy me some time to see how if it was going to develop into anything worse and I think it was then that I thought, you know what, I'm not going to let this disease get me this time. I think that's got to do with I'm in a much more comfortable place in my own life now. I've been with my partner a while, we've got our

own house, we're a lot more settled and I think there was something in me that felt for his sake I really need to give this my all and its definitely helped. (p. 25)

For E10, the needs of her partner appear to provide the motivation she required to take back control of her life.

5.1.4b Coping

The second subtheme of 'coping' highlights the variety of ways the women tried to cope with their symptoms, with not all coping techniques working for everyone. For example, some said that exercising helped them, whereas others were in too much pain to exercise

E8 - Exercise does erm, I've been going to a boot camp class and it's at night time and I'll come home from work and my stomach has been sore, I actually feel it's sore going to the boot camp class but I actually feel after the class that I feel better. So I do think exercise works and I run as well and just try and keep it up with it. Sometimes after I've run it'll actually be sorer erm but I think that's only when I push myself too much. (p. 12)

E10 - I'd think, just go out and do something, you know maybe run it off or go and exercise or something and get rid of it, then you can't cause you're in pain so you're kind of thinking well I can't really do that cause that makes me feel like this, I'm going to suffer for that and so you're constantly trying to keep yourself...just ticking over nicely and it's a struggle. It's a real struggle actually. (p. 23)

Many women used alternative therapies to help cope with the symptoms, such as massage, reike, aromatherapy, and reflexology. Most stated that although they found these therapies comforting and relaxing, which helped them cope better with the symptoms, they did not reduce

their level of pain. Other methods of coping included deep breathing, using hot water bottles, and taking hot baths. Again, these methods had mixed success.

However, for some women, one alternative form of pain management that did reduce their pain was through nutrition and diet change

E12 - I looked into nutrition and got the book by Diane Shepperdson Mills and the 'endo resolve' website took me through a lot of dietary stuff and I've managed to turn things around hugely. I'm now off the pill, I'm controlling my diet, I've been to the herbalist at Napiers and using those three different things I'm more normal than I've been since I was a teenager. (p. 2)

E13 - Round that time there was a...we went, the endometriosis society runs talks in (name of hospital) and I went to, I went to speak to them and there was a nutritionist and I listened to her talk and thought, oh ok this is kind off making a bit of sense and I made an appointment to go and see her and it ended up being a full consultation and I spoke to her and I started the diet erm in November mid November 2010. Within a week I had no pain. (p. 4)

E1, E2 and E8 also had success in reducing their pain through following a very strict diet aimed at reducing the inflammatory response that is thought to be common in many auto-immune conditions.

The use of medication was also highlighted as a common method to control the pain. However, this was not always successful and often only reduced the pain to a more manageable level as opposed to controlling it completely. Some women also talked about how they would take more painkillers than the recommended safe dosage in an attempt to lower the pain. In a sense, this

could be seen as a maladaptive form of coping as not only did it not control the pain, but it also was a potential threat to their health through an increased risk of overdosing on the drugs

E7 - The only relief I could get, not relief but I would be sitting rocking. That was how I would erm cope with it erm and I mean the amount of drugs I would take erm, more than the packets would say and you just didn't care. (p. 6)

E6 - Even like the pain medication that I took, I was on diclofenac which didn't work at that time at all and then he gave me another tablet which just used to knock me out which was perfect cause that worked but the consequences of that was I was drowsy and couldn't do very much erm so coping with the pain, I don't think I did cause I was either knocked out, I mean I tried to take the diclofenac and at points it would work; it would make it subside so that it was at a point where you could manage it, like you could you could sort of function with it. (p. 7)

E2 - What I was taking, and to be honest I would have taken even more you know erm if, if I thought for a second that it was... I could have probably overdosed on not, not intentionally, but just, just trying to get rid of this pain and you know, where there's been times where I've taken a painkiller and been sick straight away so I've went back for another painkiller cause I thought I've just brought that up there, where I don't know if I've brought it up it might still be in my system. (p. 40)

There is a sense from these excerpts of the desperation that the women felt to relieve their pain, to the extent that they were quite willing to take risks with their health by disregarding the recommended dosages of the strong painkillers they had been prescribed.

The coping techniques highlighted so far are focused on reducing pain symptoms. However, not all coping strategies were aimed at reducing pain. Some women talked about harnessing social support as a way to cope with the all-encompassing effects of the condition. Going to a support group or using online chat rooms or 'Facebook' pages helped women to feel less isolated and part of a bigger community of people who understood what they were going through

E3 - I have a very supportive family, very supportive friends, very supportive boyfriend erm but to some extent they don't know what I'm going through and I have to say that it's only been in the last...I don't know since last August that I've been on this Facebook site because I never knew anything about it. I knew about Endometriosis UK but I never knew anything about the Facebook site but, and I have to say speaking to the people on that is good. (p. 9)

E10 – It's difficult. It just seems like always you've got questions in your head all the time. There are no right and wrong answers and going to (the) support group and hearing different women's experiences, I mean we all have the same but different experience so it, it's good because you've got other people that understand it's bad because you think what if it doesn't get any better than this you know this is it. So it's just listening to other people, what decisions they've made and how it's impacted on their life, it does help. (p. 6)

One woman has become directly involved in supporting women with endometriosis and this has helped her to put her life and symptoms into perspective and given a purpose to what she has been through. Other women also echoed that they would like to help others by creating awareness and sharing their stories, coping strategies and tips

E1 - To be honest, joining the charity was another coping mechanism because I just felt that 10 years of my life had been totally wasted, compromised where I didn't have a life and I just felt that if I'd suffered for 10 years and then didn't use what I'd learned, because I'd read everything that there was to read, and I just felt if I didn't go and put that into something positive then I think it actually might have drove me quite insane that it was so pointless. (p. 28)

Regardless of the types of coping strategies that the women employed, the fact that they had made a conscious effort to do something made them feel better about themselves and that they had more control over their own health as opposed to being solely reliant on the medical profession to come up with a solution to their condition, as this excerpt from E10 suggests

E10 - One thing that she did say that always stuck with me was that knowledge is power and I think that is again, another reason why this time round I've thought, well you know what man, yeah it is going to be this time because I am going to find out as much as I can about this and as much as I can do myself to help because I don't think the onus should always be on the medical professions because there is no one pill that cures all you know, and I think I think as individuals we do need to take a bit of responsibility for our own health and try our hardest in our own way to do what we can to sort of alleviate the symptoms and the pressure that's on you. (p. 36)

This final point by E10 which deals with taking responsibility for the condition, may be an example of a shift in current western cultural beliefs that the individual is responsible for their health and illness. In this cultural climate, there is less state intervention in the lives of the population, and individuals are instead 'empowered' to take control of their lives, including their health (Galvin, 2002). There has been debate for and against this shift in responsibility for health, with the arguments for focusing on 'personal empowerment' and a way to reduce the

burden on the NHS. The arguments against however, see the individual responsibility as being equivalent to 'victim blaming' (Galvin 2002). In E10's extract, there is less of a sense of 'victim blaming' and more of 'empowerment', as she and many other women in the present study express that they have benefitted in an increase in sense of control from educating themselves and others about the condition, and from finding methods of coping which are unique and individual to their particular needs.

However, with conditions such as endometriosis, where there is no cure, no guaranteed form of treatment and often a lack of awareness of the condition within the medical profession that people are often left to search on their own for ways of managing their condition. Crawford (2006) highlights that as awareness increases in the general population of future health risks and the various actions that are recommended be taken to reduce the risk of future illness also increase, so does the awareness of the gap between the perception of danger and what can actually be done about it, resulting in anxiety. This may also be true in women with endometriosis as they find out more about their condition and actions they can take that may have the potential to reduce the impact the condition has on their lives. However, as in many cases, there is no clear guidance or evidence for these 'treatments' and women may be caught in the same spiral of control > anxiety > control as Crawford (2006) suggests, as they attempt to find the treatment that will work for them.

The use of alternative therapies, support groups and providing support for others in an attempt to try and manage their condition could represent a form of secondary control. The two-process model of perceived control, proposed by Rothbaum, Weisz and Snyder (1982), suggests that there are two processes of control. Primary control is the first process whereby people try and change their environment to suit their needs, and if this does not work, people move to secondary control, where they will try and change themselves to suit the environment. As it is not possible to cure endometriosis and many of the treatments provided to control or cure the

pain are unsuccessful (primary control), the women may be using the alternative methods to try to make themselves feel better about the situation they are in.

Although many of the women in this study were able to find alternative ways of coping with the wide range of symptoms caused by their condition, it was clear that there was not always the support available for them and many were discovering how to cope on their own. This lack of support related to the fifth and final theme, 'legitimisation', which is discussed in the next section.

5.1.5 Legitimisation

This theme dealt with the apparent lack of acceptance of the disease as a legitimate and recognised condition, by both the medical profession and the general public. The message from the women in this study was that a lack of information and awareness about the condition led to delays in being diagnosed and also led to a lack of support from both the medical profession and from those around them. The exception to this in general, was the families and partners of the women, who were witnesses to the pain and suffering the women endured.

5.1.5a Being believed by medical staff

This first subtheme highlights the lack of legitimisation of the condition within the medical profession. This was indicated by the recurrent stories from the women, who described their struggle to be taken seriously, receive a diagnosis and finally to receive treatment.

More than half of the participants waited more than the average length of time for a diagnosis in the UK of eight years (Hadfield et al., (1996)). Prior to being given their diagnosis, most had visited their GP several times in relation to the pain they were experiencing during their

menstrual cycle. Despite repeated visits, many were advised by their GP that pain during menstruation was normal and there was nothing that could be done about it. In general, many women felt that often their queries about their pain being something more serious were dismissed by doctors

E7 - They just put it down to a female and her periods that kind of thing that years ago thought well girls have painful periods and that's just what happens in life. (p. 16)

Even when endometriosis was specifically suggested as a possible cause of the pain, doctors could still reject the idea, often stating that they were too young to have such a condition and that they would grow out of it

E13 - they said that erm it was irritable bowel syndrome erm because at the time of my period I would have extremely bad diarrhoea and then I would become and then I would go back to having normal bowel movements and I said well I'm only having this issue around my period is it not more likely to be related to that and they dismissed it and I said is it possible its endometriosis, I have an aunt who has endometriosis

MC – right so you raised the issue with them

E13 – I had actually had been raising the issue with them since I was 16

MC – specifically endometriosis

E13 – yes erm I'm having these very heavy periods I'm having a lot of pain with them is it possible this could be and I felt it was dismissed out of hand; you're too young to have something like that. (p. 2)

There was a sense of frustration felt by the women who had to wait a long time to be diagnosed. This frustration seemed to come from the insistence from the doctors that what they were

experiencing was normal and what appeared to be a resistance from the GPs to referring them for further investigation

E2 - I then went back to the doctors a few times and they said try it for a bit longer, try it for a bit longer, by which time I was really tearing my hair out. I was really...I was kind of getting angry because it was kind of like, I would just go into the doctor and it was like, 'here take this', they weren't really entertaining that there was a real problem here. (p. 3)

E1 - What annoyed me, what was really beginning to get under my skin was, I'm quite a strong person and what really irritated me about it was that I couldn't make people understand me. The GPs, the gynaecologists, I felt as if I was talking in a different language, that I couldn't get it across to them. (p. 22)

5.1.5b Knowledge of medical staff

There was a mixture of responses from the women to the treatment they received from the GPs. Some were accepting of why the GPs had been unable to diagnose their condition, putting it down to a lack of knowledge about the condition and acknowledging that they are not able to know about every condition. This formed the second sub theme, 'knowledge of medical staff'

E12 - It's just the consistency and this is the part, the GP's part, is the part that's really delaying things I feel for most women and because it takes that long to, it's it's not fair to say been taken seriously because it's just a lack of knowledge I think most of the time. (p. 16)

However, some were frustrated and possibly even angry, as the delays they suffered had had serious implications regarding their future fertility. In E2's extract below, it could be interpreted

that she was annoyed at the GP for not diagnosing her sooner. However, there is also a sense that she is annoyed at herself for putting her trust in this GP, whom she believed was a good doctor

E2 – Now that I know it was quite easy for me to get diagnosed and fairly quick erm I was actually quite annoyed because I thought I had a, I thought my doctor before was good and I quite liked her and I was comfortable with her erm and now I feel a bit annoyed because I'm at the stage where my endometriosis is severe whereas if they'd have listened to me all those years ago I might not been told now I have absolutely no chance of conceiving naturally. So I suppose I feel a wee bit angry for that but on the other hand me as a person I believe everything happens for a reason. (p. 16)

Fortunately not all GPs contributed to the delay in receiving a diagnosis and some women did receive referrals to a gynaecologist

E3 - One day I went along and I saw a locum and she said 'oh well that's not right, definitely something not right here' erm whether or not its cysts or whatever, so she did a referral to the hospital. (I) got referred to the hospital erm and, within five minutes of meeting the consultant and explaining my symptoms he said to me you have endometriosis. (p. 2)

Women who had private medical insurance also seemed to receive a diagnosis faster and easier than those receiving NHS medical care. As one participant reasoned, there is not the same issue about cost as there is with the NHS, with private medical companies happy to do whatever investigations necessary

E4 - I was just so fortunate that I had private that because the private people are obviously quite happy to do investigations to get the money. I was able to get everything

done. That one guy would try this, that and the next thing if he couldn't work it out. He would refer me onto the next guy, then the next guy. If I'd been NHS I'd never have cause you would have gone for one thing and maybe they would have tried something and say 'oh we can't find anything' so that's it. (p. 21)

Unfortunately it was not always guaranteed that a positive response would be received from hospital staff performing further investigations. After being admitted to hospital in severe pain, E10 was investigated for several different possible causes, none of which were gynaecologically related. Eventually her requests to see a gynaecologist were granted and only then it was discovered that she had endometriosis

E10 – I was trying to explain to them the pain's down lower and I was having a lot of trouble with my bowel as well so I kept sort of trying to explain to them it's obviously something in this area, it's not up here, it's not. They were giving me like IVPs, like dye through my blood so they could take x-ray pictures and that's not going to show up cysts. So eventually I, I think it was the kidney doctor that I was in seeing, and I sort of said to him I says look I don't think it's got anything to do with my kidneys, I think it's to do with gynaecology; I need to see a gynaecologist and they were a little bit sceptical but I was, where I was getting investigated for the kidney problems I was actually in the hospital admitted and I think because of that I was just lucky that they, I just made enough noise I think that they thought, right let's get a gynaecologist to look at this girl and sent me down. (p. 3)

This extract is an example of how some women felt they were not listened to, and it was only when she 'made enough noise' that she was reluctantly referred to doctors who in the end diagnosed the problem.

5.1.5c Public awareness

It could be suggested that if the medical profession do not always recognise endometriosis as an accepted condition, then it is understandable that members of the public in general may find it difficult to understand and accept the symptoms presented by those who have the disease. Therefore, it is not surprising that as well as experiencing a lack of knowledge and awareness of the condition from the medical profession, the women also reported negative responses from other people, such as work colleagues and employers. Many of the participants found that people simply could not comprehend that their pain and symptoms could be so severe, forming the third sub theme of 'public awareness'

E2 - It's a horrible illness. It's really horrible erm and I think very misunderstood, I really think it is. I don't think guys and why would they, want to know that kind of thing but I think guys probably know less than women do you know but then women that don't suffer then just think how can she be that bad, mine's is a breeze. (p. 54)

E3 - I just wish that it was a little bit more...people were a little bit more educated in it erm and a little bit more educated in it in work places and things like that as well because you know sometimes its women who are the worst. Women, other women think oh 'I don't get period pains what are you on about' and sometimes it's women who are the worst and actually it's the men who are more sympathetic. Maybe it's just because they don't like discussing those types of things. (p. 25)

E10 - You can't tell anybody because when you tell them they just (makes 'tutting' noise)' just get on with it, what It can't be that sore' and you think, well actually I wouldn't like to put you in my shoes cause actually it is that sore. (p. 3)

In the work environment, this lack of awareness only served to put more pressure on the women who were already struggling to cope with the effects of the condition, with some women feeling unable to tell their employers and colleagues about it due to the possibility of receiving an unsympathetic response

E13 – HR are aware of it but erm I just think it's, it's not really the right environment. If I have to say if I was going in for surgery then I would go in and I would speak to my boss, my male boss and say look I need to go in for surgery ok, this is what it is, I've had this for this many years. Have a look at my sick record, its exemplary, it's better than some supposedly well people in this...you just don't like to worry about you know. You just don't tell them unless you need to because it'll be like 'aw she's on her period'...unfortunately that's the type of place I work in. (p. 10)

Here E13 suggests she would only disclose her condition in extreme circumstances such as having surgery due to the stigma attached to the condition and negative response she suspects she would get from work colleagues.

Again, fortunately not all employers were dismissive of their employee's condition. For example, E3 found that her employer, the Police, had been fair and supportive when she had to go on long term sick leave due to surgery and the medication she was taking for the pain

E3 - I have to say the girls at HR are being very good, very supportive erm certainly to my face, they're being very supportive but I've not heard anything to the contrary. We have an occupational health and they've been very supportive as well, erm very good. They're actually writing off to my doctor to try and get erm supportive medical erm you know erm evidence so to speak erm just about what I've got, when I got it, how many operations I've had blah blah blah erm and they've been very good as well. The

federation who we have, they've been very good saying that I should remain on full pay and things like that. (p. 17)

This general lack of awareness was also present in some of the women themselves, who up until their symptoms had become unmanageable, had accepted that painful periods were normal and therefore put up with the pain

E7 - I just thought it was normal...not the...the period part of it when you had your periods, I just thought it was normal and erm then the, the pain outwith because I kept, everybody said oh its irritable bowel and it's, so I didn't really associate it with it. (p. 7)

E2 - My mum had erm suffered bad periods as well and again probably thought this was just normal hereditary, she went through it I'm gonna go through it. (p. 1)

5.1.5d Support from significant others

In terms of personal support, all of the women in this study reported feeling very supported by their partners and mostly all by their families, forming the final sub theme 'support from significant others'. In contrast to the medical profession and the general public, partners were supportive regardless of whether they knew anything about endometriosis or not. This could be because they had directly witnessed their loved one in pain and suffering from a wide range of symptoms

E2 - You know, I'm on my knees kind of wailing really and then at points I would be trying to scream that nothing was coming out and he's rubbing my back and trying to, you know, hold a hot water bottle on me and all of this, but I think unless you've physically seen that you won't have any idea. (p. 51)

However, where participants didn't feel they were being supported, there was a sense that this was due to a lack of understanding or awareness on the part of the other person. For example, some relatives didn't appear to accept the condition and therefore were not as supportive

E13 - My dad doesn't understand. It's his sister that has endometriosis but he's, he wasn't around. He was in the army so he was away, he was deployed when she was having all the bad time so he doesn't, he's only seen her after the surgery, after she's been treated so he didn't realise that me needing to sleep in the afternoon wasn't me being lazy (laughs), it was my body needed to sleep there was nothing else for it. He's, he's starting to come round. My mum's, mum's been fantastic; she knows a bit more about the history from my aunt and things like that. (p. 10)

Some women had had previous relationships where their partners had not been as supportive as their current partners

E2 - When I was early 20s like, before I met my husband, my previous partner you know wasn't as understanding but I didn't know obviously what the extent I was dealing with... erm...erm...aye I just thought obviously was really bad periods erm...he wasn't particularly great. (p. 22)

Similarly, some women experienced the loss of friendships due to them not being able to understand the impact the condition had on their ability to take part in everyday activities associated with socialising

E13 - I've lost a lot of friends who just couldn't understand that it was still me, I just couldn't do as much as I used to do. It didn't mean I was less of a friend to them, it just

meant that we had to change what we did erm and some of them fell away. It just...it's...I don't feel sad about it though because they were just erm they weren't really friends more acquaintances. (p. 13)

Even friends who appear supportive may not always fully appreciate the full extent the symptoms can have

E12 - I remember going on my friend's hen night in Amsterdam and I was on the prostop injections. I had put on about 2 stone in a month and a half, I was sweating, I was like going through, obviously going through the menopause and I was just having panic attacks and night terrors and stuff and I shouldn't have gone on this thing but they pressurised me so much to go. It's the same, I'm friends with them now but I think when I told them about how bad it was they came back and they were like we just didn't realise, but I told them but they just weren't really taking me seriously. I think if you can't see it it's not there. (p. 5)

Some women acknowledged that their partners and family members were going through as much suffering as they were, as the partners were helpless in doing anything to ease the pain

E3 - He on a regular basis feels very helpless. If we're lying in bed and I'm in a lot of pain and I can't get comfy he goes 'what can I do?' and I'm like 'nothing' cause, it's not that I'm being horrible but there isn't anything he can do and he always says 'I feel so helpless I can't do anything'. My sister feels so helpless as well so do all my all my family feel helpless cause it's not like, (they) can't give me a kidney or can't do anything like that for me so erm...but I'm lucky that have a lot of support round about me...they are good ...overall. (p. 12)

In general, though the women in this group felt supported by those close to them. In each of the sub themes, it is possible to think about the support the women have received as being directly related to the amount of knowledge and awareness of the condition that others around them have. In the case of receiving support from the NHS and medical profession in general, those women who had GPs and consultants with experience of diagnosing and treating endometriosis found it easier to receive that diagnosis and treatment. However, those women whose GPs or consultants did not have experience of the condition faced a lengthy and painful process where they had to almost fight to receive a diagnosis and treatment. In these cases the women did not feel supported and there was a sense that they had been abandoned by the NHS to fend for themselves.

E10 - As I say there's just nothing, nobody you can go out and talk to all these things about and that's...frustrating, very frustrating. (p. 22)

The issue of lack of knowledge and awareness was viewed as a circular one, with lack of awareness resulting in the women receiving negative and unsupportive responses from others. However, there was also a lack of information and education available to improve the public's awareness of the condition. There has been a recent increase in publicity about the condition in the form of magazine articles, and television appearances from women who have the condition which is helping to raise awareness. However, many of the women in this group felt that until the medical profession take the condition seriously and that all GPs have an awareness of the condition, there will continue to be a lack of support from both the NHS and the public.

6. Discussion

6.1 Study summary

The main aim of this study was to investigate women's experience of endometriosis using an interpretative phenomenological approach. From the analysis of the 12 transcripts, 5 major themes were established: making sense, impact on daily life, identity, taking back control, and legitimisation.

The first theme of 'making sense' was related to the journey the women went through from first experiencing symptoms and recognising patterns to the realisation that these symptoms required medical attention, usually because they had become unmanageable. For many, symptoms that had been experienced for a long time changed in severity. As a result, the perceptions that the women had about their symptoms also changed, from something that was bad but manageable to something that required intervention. This process of making sense was advanced by receiving a diagnosis which provided a language to talk about the condition and access to information and support, allowing the women to understand why they experienced the pain and symptoms they did. However, although they understood why they were in pain, uncertainty remained due to the fact that there is no cure for the condition and that treatments are not always successful.

The second theme 'impact on daily life' saw the women reflect upon what their lives are like living with this condition. They presented a picture whereby most areas of life such as work, socialising and education activities were disrupted due to the condition. This concept was taken further where the women described being controlled by the condition, where they attempted to live their life as best they could by planning around their symptoms. This planning took place on both short time scales, where women would plan immediate activities depending on how they felt at that moment, and on a longer time scale, planning for events further in the future, when

they have less information about how they will feel. Another significant impact the condition had on life was the negative psychological impact with depression, hopelessness, loneliness, anxiety about the future and a fear of pain all adding to the challenges faced by the women.

The third theme focused on the impact the condition had on the women's sense of identity. Self-doubt plagued many of the women where they questioned their perception of the severity of the symptoms and ultimately their own sanity; mainly due to not being believed by medical practitioners and other lay people. The restrictions the condition placed on their ability to perform expected social roles interfered with their sense of self, with many feeling useless or less womanly as they were not able to live up to their own and others' expectations. In order to maintain their sense of identity, many women tried to conceal their symptoms and 'put on a brave face'.

Taking back control was the next major theme. This theme signified a move from being controlled by the condition, to attempting to regain control and to reach a stage where they were able to cope better with their symptoms. Often this change in attitude towards taking more of an active role in their own care was triggered by dissatisfaction with the care options presented by the medical profession and an acknowledgement that treatments were limited and their success not guaranteed. A wide range of coping techniques were highlighted, with some more successful than others. Despite this, taking more of an active role in their health had the benefit of making many women feel better about themselves.

The final theme regarded the legitimisation of the condition. Most of the women struggled with the lack of understanding and acceptance of the condition from both lay members of the public and from the medical profession, who tended to normalise the symptoms as part of being female. These responses had a significant impact on the women by causing delays in seeking help, in receiving a diagnosis and by increasing a sense of isolation.

6.2 What this study adds to the literature.

6.2.1 Relevance of findings to current Health Psychology theories

By using IPA, the focus of the research is solely on how the women experience endometriosis as a chronic condition and is less of an objective statement about the event, whilst also acknowledging the role of the researcher in carrying out the research (Smith & Eatough, 2007). Through focussing on experiences which have meaning, the women reflected on the significance of the condition in their lives and the approach of IPA allowed these reflections to be presented and engaged with (Smith et al., 2009). In the telling of their experiences, the women highlight the complexity of living with a chronic condition which is made all the more complex due to its perceived legitimacy and its relationship to gender. The context in which the women experience the consequences of the illness has implications for what these experiences mean to them. Quantitative studies have found that women diagnosed with endometriosis experience a reduced quality of life. However, they do not explain why this is the case. The use of IPA in this study and its focus on interpretation helps us to develop a deeper understanding of not only the impact that the condition has on women and what it means for their lives, but also how culture and society influences the experiences of the women who live with this condition.

As discussed earlier, two health psychology models which examine how individuals cope with illness are the CSM (Leventhal et al, 1980) and the TCA (Taylor, 1983). The findings of this study support the CSM in that women can be seen to search for the identity, cause, cure/control, timeline and consequence of the condition. Similarly, women demonstrate an emotional response to the condition in the form of anxiety and fear of recurring pain and the impact on their future life and fertility. Women also engage in a variety of coping actions in an attempt to alleviate or manage their condition. In this sample at least, there did not appear to be any additional forms of illness representations specifically relevant for endometriosis not already

defined by the model. What the study does provide is the detail of each of the CSM constructs, For example, the identity of the condition is not always clear and this depends on the individual's knowledge and experience of painful menstruation and other symptoms and whether they know other people who have been diagnosed. If the women in their family have always experienced painful menstruation and it is accepted as 'women's problems' then they may identify their symptoms as a natural part of female life. On the other hand, if they know someone who has been diagnosed with endometriosis and identify with their symptoms, they may be more likely to question the symptoms.

Similarly, we are more aware of the emotional response women have to the condition and this appears to be related to the uncertainty around the cause, the cure/controllability and the consequences of the condition. This uncertainty impacts on the women's coping actions in that as well as orthodox medicine, women are willing to try a variety of non-evidence based techniques in order to manage their symptoms. However, as these methods are not guaranteed to work, the appraisal stage of the model leads them back to the illness representation stage without reaching a state of equilibrium, as the model suggests. This is where it seems women get 'stuck' in the cycle, constantly looking for different coping actions which will lead them to a state where they are successfully managing with the condition. Unfortunately in chronic, progressive conditions with no known cure, many do not find that state of equilibrium. It is possible that instead of coping actions which are focused on alleviating the symptoms, alternative coping actions which focus on acceptance and how the individual interprets their condition and their life now, may help individuals to reach a state where they are managing the condition but maintaining as good a quality of life as is possible for them.

Similarly, the findings of this study have relevance for the TCA (Taylor, 1983) also. The women do engage in a search for meaning and in the absence of a definitive cause, they will look to their own experiences to find a reason for developing the condition that makes sense to them.

Unlike Taylor's (1983) finding with women diagnosed with breast cancer however, few of the women in the present study found any benefits from living with the condition. The women all tried to gain mastery over the condition through the use of a variety of coping techniques and education. The women in the present study did not openly make downward social comparisons in an effort to increase self-enhancement however, and although not explicitly stated, there is a sense that they made upward comparisons, to women who do not have such problems with their monthly cycle and are able to 'cope' with it. As suggested throughout the analysis, this could be due to the moral aspects of illness and in particular the assumptions that are made within the medical field and the lay public that pain during menstruation is normal and should be managed.

Therefore, although health psychology has identified models which may guide our expectations as to how someone will adjust to living with a chronic illness, they do not provide the intimate details which are necessary to fully understand what living with a chronic illness is like. Without this insight, health psychology models have limited use in contributing towards making a difference to the lives of women with endometriosis. Through the use of careful listening involved in the IPA approach, it is possible to add the real world detail that these models need in order to be employed in supporting individuals with this condition. The specific contributions that this study has added to the literature are now discussed in more detail.

6.2.2 Original contributions to the literature

The findings of this study do echo the results of other qualitative studies, with all five themes being highlighted to some degree. However, four of the five themes in the present study have raised additional issues which increase our understanding of the significant and meaningful aspects of living with endometriosis, which are useful when considering implications for practice or future research.

In the theme of 'making sense' the present study suggests that women go through a process which takes place over a period of time, in order to understand what is happening to them. Although other studies highlighted similar issues such as the experience of pain and symptoms, delays in diagnosis and diagnosis and the women's attempts to self-manage the condition (Ballard et al., 2006; Denny, 2004a; Denny, 2004b; Denny & Mann, 2008; Gilmour et al., 2008; Jones et al., 2004; Manderson et al., 2008), these studies looked at different points during the illness trajectory as opposed to an on-going process of experience. For example, Whelan (2007) discusses how women obtain knowledge and become expert patients; however, this process occurs after diagnosis takes place and does not look at the whole journey.

Some research has suggested that the process of making sense can lead to better adaptation to the condition. As already highlighted, searching for meaning is one of the factors involved in the readjustment process according to the TCA (Taylor, 1983). Similarly, other theories suggest that making sense is important to adaptation where positive growth can be an outcome from the experience of suffering (for example, Gillies & Neimeyer, 2006; Joseph & Linley, 2006; Tedeschi & Calhoun, 2004). The theory proposed by Gillies & Neimeyer (2006) suggested that in coping with bereavement, individuals first attempt to make sense of why the loss has occurred. The second part of the process involves finding benefit in the situation by creating new meanings and looking for positives that have arisen from the experience of loss. Finally, a change in identity occurs from the process of reconstructing the meaning that is attributed to life. This process could be extended to those living with a chronic illness. In the case of the women in the present study, many were still trying to make sense of the condition. In particular, to understand what causes it, why they had been affected in particular and searching for a cure or a successful treatment. Few highlighted benefits of the condition, with the exception that some recognised that they had become more knowledgeable about the condition which made them feel more in control, and one woman acknowledged that she had become more tolerant towards others since living with the condition. As will be discussed in the third theme, many

women were trying to maintain past identities, which could suggest that they had not reached a stage of integrating the condition into a new identity. As this present study only sought to initially explore the lives of women with endometriosis at one single time point it is not possible to know how the women will adapt to the condition in the future. However, many women had lived with the condition for several years so it may be the case that women with endometriosis struggle to adapt to the condition, suggesting more needs to be done to support women to adapt to living with a chronic illness. Future qualitative studies which follow women with symptomatic endometriosis to further explore how the process of making sense progresses throughout the course of the condition would be beneficial. Having an appreciation of the sense making process in endometriosis could then be incorporated into practice whereby self-management programmes and other therapeutic interventions could include strategies that facilitate the meaning making process, thus supporting adaptation to the condition. For example, mindfulness based stress reduction programmes, which promote a non-judgemental awareness of our on-going mental processes, have been found to enhance 'coping with distress and disability in everyday life as well as under more extraordinary conditions of serious disorder or stress' (Grossman, Niemann, Schmidt & Walach, 2004, p. 39), and may support women to manage their experience of pain and become aware of how they are responding to their experiences.

In the second theme of 'impact on daily life', the present study had more of a focus on the psychological impact of the condition than in other studies which highlighted similar themes (Denny, 2004a; Denny, 2004b; Denny, 2009; Denny & Mann, 2007; Denny & Mann, 2008; Emad, 2006; Gilmour et al., 2008; Huntington & Gilmour, 2005; Jones et al., 2004; Manderson et al., 2008; Seear, 2009a). It is clear that the women who participated in this study experienced a range of emotions, such as anxiety, guilt, hopelessness and fear. Many of these emotions were a result of uncertainty regarding the condition and how it would affect the women's futures.

Illness uncertainty has been defined as being unable to predict outcomes due to a lack of sufficient cues and also if it is not possible to 'determine the meaning of illness related events' (Mishel, 1990, p. 256). Mishel also found that the degree of illness uncertainty experienced is related to the complexity of the treatment/health care process, the ambiguity of the illness, whether the course and prognosis of the disease is predictable or not and how much information is available about the diagnosis. It has been suggested that illness uncertainty, if perceived as a threat, can change how acute pain is perceived and can negatively influence how people adapt to chronic pain (Wright, Afari, & Zautra, 2009). In a study of women with endometriosis, Lemaire (2004) reported that emotional distress was positively correlated with illness uncertainty, which in turn was associated with the unpredictable nature of the condition. As discussed previously, making sense is part of the adaptation process and therefore high levels of uncertainty can have a negative impact on adjustment. As endometriosis has an unknown aetiology, no cure and is unpredictable in nature, the provision of accurate and timely information becomes even more important as a method of supporting women to cope with the uncertainty caused by the condition. Some women in this study felt that they had been left to fend for themselves in terms of finding information about the disease, increasing their illness uncertainty and feelings of isolation and abandonment. Therefore, having reliable information provided as early as possible, even as early as in adolescence, may help women to reduce the levels of illness uncertainty and any emotional distress this may cause (for example, Ballard et al., 2006; Manderson et al., 2008). This could include the development of educational initiatives, delivered as part of secondary school education to advise young women what to look out for, as well as leaflets available through health centres, hospitals and community services, especially those often frequented by women.

The present study also highlighted that in relation to the experience of dyspareunia, some women described how they had developed a phobic response to having sex, which compounded any problems they already experienced with sexual activity. This is an important

aspect for health professionals to be aware of, as it suggests that even if women are not currently experiencing dyspareunia, they may still experience on-going psychological consequences, with the potential to result in long term sexual dysfunction, relationship and quality of life issues. If health professionals are aware that dyspareunia has been a problem in the past, simply enquiring about any remaining concerns relating to sexual activity may be enough to initiate a dialogue regarding the psychological impact of pain during sex. A self-help intervention based on cognitive behavioural therapy (CBT) could be devised to support women and their partners overcome the phobia and facilitate a return to acceptable levels of intimacy. If this was unsuccessful, however, referral for more intensive or face to face couple therapy may be required.

From the theme of 'identity', the present study highlighted that the women avoided disclosing the extent of their symptoms to others in an effort to maintain their sense of identity and to prevent people from viewing them negatively. Choosing not to disclose details of symptoms or the severity of them is common in many chronic hidden illnesses. As well as trying to maintain identity, others find that by not telling others, they can maintain their past identity and they can deny the reality of their condition both to themselves and to others (Charmaz, 1993; Charmaz, 1999). This is an important point for healthcare professionals to be aware of. As one woman (E1) in this study highlighted, she was reluctant to disclose the severity of her pain even to her doctor for fear of being judged as a hypochondriac. Health care professionals can gain a fuller picture of women's symptoms by asking not only about the level of pain they are experiencing, but also asking about the quality, duration and frequency of the pain or the extent to which it disrupts their activities of daily living (Denny, 2009). In order to facilitate communications between women with endometriosis and health professionals, as well as providing widely available information on the symptoms of endometriosis, educational leaflets could also provide a template consultation for women to use so that they are aware of essential information that can help their GP or health professional to make a clinical evaluation of their symptoms. The

UK charity Endometriosis UK provide such a resource, however, unless the woman is aware that she may have endometriosis, she may not be aware that this resource exists. Similarly, additional education sessions, such as the Practice Based Small Group Learning (PBSGL) (NHS Education for Scotland (NES), n.d) continuing professional development programme, could be delivered to raise awareness of the specific issues related to endometriosis, its diagnosis and its treatment.

Finally, the issue of 'legitimation' or acceptance of the condition has been raised in many studies previously and the present study also echoes these findings. Similar stories were heard from women regardless whether they had received a diagnosis recently or many years ago. Unfortunately, this may suggest that, despite an increase in awareness of the condition through the work of endometriosis charities, women still face the possibility of having their symptoms normalised by their doctors when they first present with symptoms. Although not reported in the analysis, in this sample of women there was the suggestion that those who had private medical insurance received a diagnosis quicker. For these women, they decided to use private medical care often after attending their NHS practitioners unsuccessfully and in general, reported that symptoms were less likely to be normalised in comparison to when they attended their NHS doctors. It was appreciated by the women that due to the financial aspect of private care that these doctors were not restricted in terms of the type and number of investigations they were able to perform, and that the NHS is more restricted in that sense. However, it could be questioned why many NHS doctors in this sample tended to normalise the symptoms whereas private medical doctors did not. Other studies have called for an increase in education for GPs in endometriosis (Denny & Mann, 2008; Huntington & Gilmour, 2005) and this is still required (for example, via the PBSGL continuing professional development programme as proposed above). However, up until recently in Scotland there has not been a defined care pathway for the treatment of pain conditions. Since 2009, NHS Scotland has been developing a pain treatment pathway which will create a clearer route to treatment for pain conditions and access

to pain self-management programmes (NHS Education for Scotland, n.d). As part of this redesign of pain services, an education group has been set up with the aim of educating healthcare professionals and the public about chronic pain. Although this will not improve healthcare professional or the public's knowledge of endometriosis per se, it may improve the way in which this most distinctive and disruptive symptom of the condition is managed. Future research should investigate whether this change to management of pain conditions does in fact have an impact on the management of endometriosis.

6.3 Other implications for future research

As well as the implications for practice and future research discussed in the previous section, the results of the present study have also highlighted two other areas that would be advantageous to investigate.

One issue that was raised by many women was that they felt they were unable to communicate with their doctors about how bad their symptoms were. As coping with a chronic illness generally requires interaction with medical professionals, the beliefs held by medical professionals about a woman's symptoms and about endometriosis as a disease have an important contribution to how the woman will respond to it. For example, if a GP believes that endometriosis only affects older women, then the medication, advice and referrals offered to an adolescent presenting with severe menstrual pain will be different from that offered to a woman in her thirties. As well as having an impact on the treatment the adolescent would receive, it also has implications for the way that she may respond to her symptoms in the future (for example, self-doubt or normalisation). Further qualitative research into the experiences of doctors who care for women presenting with symptoms suggestive of endometriosis, would be useful to highlight areas where beliefs of the patient and the doctor are different.

Similarly, for conditions that are chronic, day to day self-management of the symptoms is the aim for most individuals and their doctors. As a result the NHS attempts to provide support for people who are living with chronic conditions through the provision of self-management interventions and programmes. In theory, women with endometriosis could be suitable candidates for participating in these types of programmes. However, although the aspects of living with the disease highlighted in this study are consistent with models of self-management, it is unclear what successful self-management looks like to both the women who have the condition and to the GPs treating them. Further qualitative research to ask this question would be useful to guide women in their responses to the condition and its treatment, and also to guide the medical professionals in the self-management advice they give to women (Kralik, Koch, Price, & Howard, 2004).

6.4 Limitations of the study

It is necessary to highlight the limitations of this study. The women who took part were recruited through contact with an individual who ran an Endometriosis UK charity support group. Although not all of the women had attended the support group, the fact that they all had contact with the charity could suggest that they had access to information and support through the sharing of experiences. It could also suggest that these women experienced more severe symptoms prompting them to seek more support. Women with endometriosis recruited using different methods may have resulted in a sample of women with less severe symptoms and as a result, they may have reported different experiences. It is known that not all women with endometriosis are symptomatic, and therefore a different sample recruited using different methods may have included women for whom their symptoms were not as severe or disruptive or which had different consequences. This is supported by the negative case analysis in this study, which highlighted that not all women with a diagnosis of endometriosis will experience debilitating pain.

Another limitation of this study is that it did not include participants from any ethnic minority groups. As the experience of endometriosis is influenced by social and cultural factors, the themes emerging from the data may have been different had the participants been from a mixed ethnic background. The Endocul study by Denny, Cully, Papadopoulos & Apenteng (2010) showed that although many issues were the same regardless of ethnic background, some issues specific to culture or religion were identified. For example, concerns regarding gynaecological examinations, treatment with contraception, privacy and lack of communication support were all raised by women over and above the concerns raised by dominant ethnic groups. Therefore future qualitative research should take measures to increase the accessibility of research projects about endometriosis to women from ethnic minorities.

7. Conclusions

In conclusion, this IPA study of women's experiences on endometriosis has echoed similar issues highlighted in previous qualitative studies and further highlights the process women go through in trying to make sense of the condition and the negative impact of the condition on women's sense of identity and psychological outcomes. However, by using IPA, It has been possible to not only look at what it means to live with endometriosis, but also consider how the culture and society can influence these meanings and therefore their experiences.

Health psychology has a focus on self-management of chronic conditions and has yet to have examined endometriosis in particular, despite affecting a large number of women and despite the lasting negative impact of the condition on quality of life. Health psychology could contribute to improvements in the way this population are supported in self-managing their condition through on-going qualitative research which investigates how women make sense of the condition over time and whether they are able to fully adjust to living with the disease. In

addition, exploring what self-management looks like to women with endometriosis would support the development of patient-centred self-management interventions. Finally, as well as being active in the development and promotion of education for medics, the lay public and young women, health psychology can also add to existing knowledge by investigating the experiences of the health professionals who treat women presenting with menstrual or pelvic pain, thus providing a balanced platform to address issues such as legitimisation of the condition.

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Appendix 1 Sample Interview Questions

“Experiences of Women with Endometriosis”

Adapted from Weinman, J., Petrie, K., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: A new measure for assessing the cognitive representation of illness. *Psychology and Health*, 11, 431-445.

and

Goodman, D., Morrissey, S., Graham, D., Bossingham, D. (2005). Illness Representations of Systemic Lupus Erythematosus. *Qualitative Health Research*, 2005 15: 606

- 1) Demographic and background details: a) how long been diagnosed? b) How long before received a diagnosis? c) How long did you experience symptoms before going to the doctor?
- 2) a) What symptoms do you experience that are due to your endometriosis; what happens when you have symptoms? (e.g. do you have any warning they are going to happen?)
- 3) a) What do you think has caused your endometriosis? b) What do you think is happening inside your body when you experience symptoms?
- 4) a) How has having endometriosis affected your life? b) In what way do you think having endometriosis will affect your future? c) How has having endometriosis affected your relationships with others you are close to?
- 5) a) What kinds of things do you do to cope with the symptoms of your endometriosis b) What kinds of things do you do to cope with the consequences of your endometriosis (e.g. infertility, being absent from work etc) c) what is the best thing that helps your endometriosis? d) is there anything that you know does not help?
- 6) What do you think about the medical care you have received in the past in relation to your endometriosis? (If negative – What could have made this a better experience?)

Appendix 2 Participant Information sheet



Queen Margaret University
EDINBURGH

Postgraduate Research Project

My name is Michelle Clark and I am a postgraduate student from the School of Arts, Social Sciences and Management at Queen Margaret University in Edinburgh. As part of my doctoral degree course, I am undertaking a research project for my thesis. The title of my project is: Experiences of Women with Endometriosis.

This study will investigate how women with endometriosis manage the symptoms and outcomes of the condition.

The findings of the project will be valuable as to date, there has been limited research carried out which investigates the experience of living with this condition.

I am looking for volunteers to participate in the project. In order to take part in the study, you will have received a surgical diagnosis of endometriosis, be over 16 years of age and be able to speak and understand English language.

If you agree to participate in the study, you will be asked to take part in a face to face interview which will be recorded using a digital voice recorder. On average, interviews can take between 1 and 1 ½ hours, but not usually longer than this. The interview can take place at a location suitable to you.

The researcher is not aware of any risks associated with taking part in a face to face interview. You will be free to withdraw from the study at any stage and you would not have to give a reason.

All data will be anonymised as much as possible, but you may be identifiable from tape recordings of your voice. Your name will be replaced with a participant number, and it will not be possible for you to be identified in any reporting of the data gathered.

The results may be published in a journal or presented at a conference.

If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact Dr Vivienne Chisholm. Her contact details are given below.

If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, please now see the consent form.

Contact details of the researcher

Name of researcher: Michelle Clark

Address: Postgraduate Student,
Health Psychology Department,
School of Arts, Social Sciences and Management
Queen Margaret University, Edinburgh
Queen Margaret University Drive
Musselburgh
East Lothian EH21 6UU

Email / Telephone: 07007034@gmu.ac.uk / 0131 537 9125 (work)

Contact details of the independent adviser

Name of adviser: Dr Vivienne Chisholm

Address: Senior Lecturer,
Psychology Department
School of Arts, Social Sciences and Management
Queen Margaret University, Edinburgh
Queen Margaret University Drive
Musselburgh
East Lothian EH21 6UU

Email / Telephone: vchisholm@gmu.ac.uk / 0131 474 0000

Appendix 3 Consent Form

Postgraduate Research Project



Queen Margaret University
EDINBURGH

“Experiences of Women with Endometriosis.”

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason.

I agree to participate in this study.

Name of participant: _____

Signature of participant: _____

Signature of researcher: _____

Date: _____

Contact details of the researcher

Name of researcher: Michelle Clark

Address: Postgraduate Student,
Health Psychology
School of Arts, Social Sciences and Management
Queen Margaret University, Edinburgh
Queen Margaret University Drive
Musselburgh
East Lothian EH21 6UU

Email / Telephone: 07007034@gmu.ac.uk / 0131 537 9125

Appendix 4 Interview Sheet

Endometriosis Study

Participant Number:

Interview form

Date of interview:

location:

Time:

Name:

Dob:

Year of diagnosis (or age):

Age of first symptoms:

Marital status:

Occupation:

Appendix 5 Participant debriefing sheet



Queen Margaret University
EDINBURGH

Endometriosis Project - Debriefing information

Thank you for generously contributing your time and sharing your experiences as part of this research project.

The main objective of the project was to find out more about women's experiences of endometriosis. As you will be aware, this common condition, experienced by approximately 10% of women worldwide, can have a negative effect on all aspects of life, health and wellbeing. Unfortunately, there is a lack of research on the way this condition affects women's lives. Therefore, it is hoped that this project will help to add to what we know about the impact the condition has and may also suggest ways in which things can be improved for those who have the condition.

I appreciate that talking about your condition and the affect it has had on your life may have been upsetting. If you feel that taking part in this research has raised issues that you need to discuss further, you may find it useful to contact one of the endometriosis organisations available. These organisations have websites which contain lots of information and support.

Endometriosis UK

Website: www.endometriosis-uk.org

Free phone helpline number: 0808 808 2227 (check website for helpline opening times)

Other support: Details of local support groups you can attend; online community/forum

Address: Suites 1&2, 46 Manchester Street, London, W1U 7LS

Telephone: 020 7222 2781

Fax: 020 7222 2786

Email: admin@endometriosis-uk.org

Twitter: www.twitter.com/endometriosisUK

Facebook: www.facebook.com/endometriosisuk

Media enquiries: 020 7222 2781

Endometriosis SHE Trust

Website: www.shetrust.org.uk

Telephone number: 08707 743665

Email: shetrust@shetrust.org.uk

Address:

Endometriosis SHE Trust (UK)

First Floor, The Chestnuts
New Cross Hospital
Wednesfield Road
Wolverhampton
WV10 0QP

Endometriosis in the UK (you are not alone)

Website: www.endometriosis.org.uk

This website was set up by a woman who has endometriosis and contains lots of information, stories and an online community/forum.

The Pelvic Pain Association

Website: www.pelvicpain.org.uk

Pelvic Pain Support Network
PO BOX 6559
Poole
Dorset
BH12 9DP

info@pelvicpain.org.uk

There are also several books available which may be helpful:

The Endometriosis Sourcebook

Mary Lou Ballweg, Editor; 1995 (McGraw-Hill Contemporary)

Alternatives for Women With Endometriosis : A Guide by Women for Women

Ruth Carol, Editor; 1994 (Third Side Press)

Endometriosis : A Natural Approach

Jo Mears; 1998 (Ulysses Press)

Endometriosis-One Woman's Journey

Jennifer Marie Lewis; 1998 (Griffin Publishing)

Fibroid Tumor and Endometriosis Self Help Book

Susan M. Lark; 1996 (Celestial Arts)

Natural Treatment of Fibroid Tumors and Endometriosis

Susan M. Lark, MD, Phyllis Herman (Editor)

Endometriosis: Healing Through Nutrition

Dian Mills, Michael Vernon; 1999 (Element)

Endometriosis: A Key to Healing and Fertility Through Nutrition

Michael Vernon, Dian Mills; 2002 (Thorsons)

Living Well with Endometriosis: What Your Doctor Doesn't Tell That You Need to Know

Kerry-Ann Morris; 2006 (Harper-Collins)

If you have any questions about the project, please do not hesitate to contact me on

Tel: 0131 537 9125

Email: 07007034@gmu.ac.uk

If you would like to talk to someone from Queen Margaret University who knows about the project, but who is not directly involved, please contact:

Dr Vivienne Chisholm
Senior Lecturer,
Psychology Department
School of Arts, Social Sciences and Management
Queen Margaret University,
Edinburgh
EH21 6UU

Email / Telephone: vchisholm@gmu.ac.uk / 0131 474 0000

In the unlikely event that you wish to make a complaint regarding any aspect of this project, please contact Dr Chisholm, in the first instance. Queen Margaret University has a complaints procedure for research in place, the details of which can be found at www.qmu.ac.uk/research.../Code%20of%20Practice-January%202009.doc .

Once again, thank you for taking part in this project.

Michelle.

Appendix 6 Super-ordinate & sub themes across group

Super	Sub theme	E1	E2	E3	E4	E5	E6	E7	E8	E9	E10	E12	E13	
1	a patterns / symptoms	2	6	3	9	0	3	3	4	2	2	2	4	11/12
	b gradual worsening of symptoms	1	2	5	0	0	0	2	3	1	2	2	1	9/12
	c diagnosis – helping to understand / benefits of diagnosis	4	7	0	4	1	4	0	0	0	2	0	1	7/12
	d realisation no cure	5	0	3	1	0	0	0	2	1	2	0	0	6/12
	e realisation of fertility issues	0	1	2	1	3	0	0	0	0	0	0	0	4/12
	f understanding cause	4	0	1	3	1	1	0	2	1	1	0	1	9/12
2	a disruption / interference with daily life	3	8	6	7	8	5	3	9	6	6	3	10	12/12
	b taking over life / lack of control / not in control of life/ planning	4	12	2	3	0	0	1	1	3	4	1	0	9/12
	c psychological impact	2	9	8	13	3	8	0	4	6	22	5	4	11/12
3	a questioning self	2	2	0	1	1	3	0	0	0	1	0	2	7/12
	b masking reality – trying to maintain identity	5	2	2	1	0	0	4	1	1	0	1	0	8/12
	b changed identity	3	0	3	2	3	2	1	2	1	2	7	3	11/12
4	a coping triggers	1	0	5	1	0	0	2	2	0	1	3	0	7/12
	b coping techniques	8	9	6	5	5	8	13	10	14	15	5	10	12/12
	c not coping	1	1	0	0	0	3	0	0	0	0	0	0	3/12
	d Benefits	0	4	0	0	0	0	1	0	0	0	1	0	3/12
5	a medical care	6	8	6	7	2	4	2	7	3	8	5	1	12/12
	b relationships	1	8	2	1	2	0	0	1	2	0	2	5	9/12
	c public / others – knowledge vs lack of knowledge	2	2	3	0	2	1	4	2	0	9	3	4	10/12

